# The Characteristics of Conducting Research with the Participation of Persons with Psychosocial Disabilities and/or Mental Health Problems

## Guide

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This guide highlights the methodological and ethical characteristics of conducting mental health research and the nuances of adherence to the principles of accessibility and “Do No Harm.”
This guide is not intended to be applicable to clinical research. It may be applicable to clinical research insofar as the individual sections of the guide are relevant. The guide can be useful in conducting research on mental health or other fields related to mental health, as well as in any role involving persons with psychosocial disabilities and/or with mental health problems.

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# INTRODUCTION

## The Importance of Research in Developing Policy on the Rights of Persons with Psychosocial Disabilities and/or Mental Health Problems

To get a complete and accurate picture of a problem, or any issue and situation, it is necessary to study it comprehensively, impartially, and professionally. These studies are carried out based on different types of research.

Research can be viewed as any collection of information and (or) use of data to understand, explain, predetermine (predict), manage and/or change the actions or behaviors of people, animals, and objects. With such a definition, we can assert that all research must be subject to accepted social norms and values.[1] These norms and values are regulated by various means at personal, systemic, local, national and international levels, and are continuously monitored to provide safe and profitable research results.[2]

There are many challenges to ensuring respect for a person's physical and mental integrity, dignity, and rights while conducting research with human involvement. Depending on the type of research, they can be expressed as double trauma prevention, respect for personal life, equality, informed consent security, and other issues. Such questions are more acute in the case of vulnerable, marginalized, or historically discriminated and stigmatized group individuals, including those with psychosocial disabilities and/or mental health problems.

According to the data of the Ministry of Health of RA, by the end of the year 2019, 57,164 individuals[3] with mental health problems were registered in Armenia, according to research, 11.19% of the population in Armenia has mental health problems.[4] Research shows a low level of access to mental health care services in Armenia, combined with a lack of adequate services and a social stigma towards mental health issues.

The need to bring to light the situation and the needs in the field of mental health is high, especially taking into account the consequences of the coronavirus epidemic of recent years, and the second Artsakh war,[5] and the fact that the system of this field services does not respond to the real needs of the population and the principles of ensuring rights, and is mainly focused on large hospitals.

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[1] Handbook of Research Ethics and Scientific Integrity: Editors Ron Iphofen: Springer Nature Switzerland AG 2020 DOI https://doi.org/10.1007/978-3-030-16759-2

[2] Ibid.

[3] Statistical Yearbook “Health and Health Care”, 2020. https://www.moh.am/uploads/2020TG-arm.pdf

[4] Pinchuk, I.; Yachnik, Y.; Kopchak, O.; Avetisyan, K.; Gasparyan, K.; Ghazaryan, G.; Chkonia, E.; Panteleeva, L.; Guerrero, A.; Skokauskas, N. The Implementation of the WHO Mental Health Gap Intervention Guide (mhGAP-IG) in Ukraine, Armenia, Georgia and Kyrgyz Republic. Int. J. Environ. Res. Public Health 2021, 18, 4391. https:// doi.org/10.3390/ijerph18094391

[5] Markosian C, Layne CM, Petrosyan V, Shekherdimian S, Kennedy CA, Khachadourian V. War in the COVID-19 era: Mental health concerns in Armenia and Nagorno-Karabakh. Int J Soc Psychiatry. 2021 Mar 18:207640211003940. doi: 10.1177/00207640211003940. Epub ahead of print. PMID: 33736534.

This Guide will provide an opportunity to develop the capacity for mental health research in Armenia and to improve the quality of research.

The objectives of the Guide are to:
- summarize the available positive experience of legal and ethical norms during the implementation of the research;
- improve guidelines by mapping, localizing, and developing existing experiments that can be a helpful tool for researchers;
- state the need to assess the impact of various situations and circumstances on persons with psychosocial disabilities and/or mental health problems, as well as the need for both targeted and cross-sectoral research within the framework of human rights and social and health field research.

The additional purpose of the Guide is to build a sense of a need to study the impact of the problem on persons with psychosocial disabilities and/or mental health problems in any type of research if there is a reasonable assumption that the study could identify specific situations in this group. By highlighting the implementation of thematic research that enables to identify a situation from the viewpoint of the rights and needs of persons with psychosocial disability and/or mental health problems, the Guideline emphasizes the need for providing inclusion and cross-sectoral research within the framework of each research. The guideline can be useful not only for researchers studying issues of persons with mental health problems but also for those who want to include this issue or ensure that persons with mental health problems participate in their research.

The available positive experience of legal and ethical norms of research has been summarized through the study of the experience of the international and national legal fields and in other countries. The standards set by the UN Convention on the Rights of Persons with Disabilities (hereinafter referred to as the UN Convention), the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being about the Application of Biology and Medicine (Oviedo Convention)[6] are essential, insofar as they do not contradict the UN Convention. The guideline targets research involving persons with psychosocial disabilities and/or mental health problems, but these legal and ethical provisions may apply in other cases as well, as they are universal in terms of respect for the dignity and rights of each individual; on the other hand, the researcher may often not know what path and personal experience the research participant has.

It is also necessary to take into account that the group of persons with psychosocial disabilities and/or mental health problems are not homogeneous. The group of persons with psychological and/or mental health problems is as diverse as other groups in society. The impact of situations on them can vary depending on individual (gender, age, ethnicity, etc.) and environmental (place of residence, environment, etc.) factors. Research on persons with mental health problems should

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[6] Armenia ratified the Convention on the Rights of Persons with Disabilities in 2010, but has not yet ratified the Oviedo Convention.

reflect a variety of factors as well. The problems of this group are subject to study not only by medicine but also by other professions altogether, cross-sectoral or individual, for example, political science, law, economics, history, etc.

The guide does not address the clinical trials and their specifics, however, the principles for working with persons with mental health problems are generally the same and can be applied to clinical trials.

The well-being of research participants should be at the center of the research process. The promotion of well-being is the protection of the principles and values deriving from and/or resulting from the rights of the participants. Planned or anticipated benefits of research should never be a reason to restrict the rights of individual participants of research.

The ethical values of dignity, self-management, participation, and accessibility must be maintained throughout the research process and outweigh any potential benefits of the research. It is necessary to consciously approach the preservation of these values in the designing and planning stages, as well as throughout the research. You can read more about the legal and ethical issues in research in the section dedicated to this topic. As we talk about the different methods in the guide, you will come across more detailed practical tips.

The guide provides brief information on research types, design, and methods, data summarization, analysis, and preparation of reports. The guide describes the need to ensure participation and accessibility for persons with psychosocial disabilities and/or mental health while the use mentions actions and certain methods.

The guide also addresses the specifics of literature review, legal analysis, human rights monitoring, and open-source research in terms of the rights of persons with psychosocial disabilities and/or mental health problems.

At the end of each section of the guide are links to literature references used to develop the content of this section, which will help to obtain additional information on the topics covered. In cases where we have used the authors' direct rather than universally accepted approaches, references to the sources of those citations are given in the text.

# 1. CHARACTERISTICS OF THE DEVELOPMENT AND IMPLEMENTATION OF A RESEARCH PROJECT

*This section provides basic information on the development of a research plan, the stages of research, the use of individual research methods, and the specifics that should be considered while conducting research on the rights of persons with psychosocial disabilities and/or mental health problems.*

## 1.1. Types of Research

The most common classification of research is:

- Quantitative research
- Qualitative research
- Mixed research

**Quantitative Research**

To conduct quantitative research means to think about the measurability of social reality, the representation of that reality, and generalizations about society (objective rules). Experts interested in quantitative research believe that it is important to find out the objective reality with possibly accurate methods.

Quantitative research is expressed in numbers and graphics. This type of research can be used to establish generalized facts about the problem.

**Qualitative Research**

Qualitative research values personal and subjective life experiences.

Qualitative research is expressed in words. It is used to understand thoughts or experiences. It provides thorough information on less well-understood, unstudied topics.

The findings and quality of each type of research can be affected by bias and prejudice, but in qualitative research, the risk of re-establishing prejudice is higher because the researcher is more involved in the data collection, interpretation, and analysis process. According to some authors, the presence of researcher approaches in qualitative research is inevitable. Other authors believe that there is a correlation between the research findings and the epistemological assumptions stated by the researcher, which may be the basis for criticizing qualitative research, especially in terms of accuracy of the information and impartial presentation.

**Mixed Research**

These research method is used in the case when it is not possible to find the answer to the research question by only quantitative or qualitative methods. Mixed research methods combines qualitative and quantitative research methods, which gives a more complete picture.

Mixed research is often used in behavioral and social sciences, especially when conducting research in a complex social environment requiring multidisciplinary approaches.

## 1.2. Research Design

One of the most important steps in conducting research is choosing its type, i.e. the research design. Research design is the processes of data collection, analysis, interpretation, reporting and statement submition. These procedures help clarify the underlying logic of the research process and the choices made before starting the research.

It is accepted to distinguish 5 basic research design types.

1. Case study as a research method or methodology is most applicable in situations where the research questions assume or contain "how" and/or "why" questions, or intend to explain a current situation, how or why a social phenomenon operates. Case studies are also relevant in situations where the research questions suggest a thorough description of a social phenomenon. Case studies are often found in various areas of social sciences: psychology, sociology, political science, business, education, community planning, etc. Case study data can be obtained from a variety of sources: documents, archives, interviews, direct observations, participant observations and material (physical) items. The advantage of a case study is that it allows the researcher to gather substantive information about one person or one case. However, often the gathered information about the experience of one person or group of persons cannot be easily used or define the experience of other persons and, therefore, it may have limited use. An example of a case study is the study of the sleeping pattern of a child with autism over five years.

2. The main objective of crossover design is to detect relationships (correlations) between two or more variables occurring in the same environment. A variable is any factor, phenomenon or representation that is attempted to be measured and studied during research. Correlational studies do not reveal causes or effects; they only show ties between two or more variables. Correlational studies can gather a large amount of information about a large number of people. The limitation of correlational studies is that it is not possible to control other factors, variables outside the study that may affect the findings of the study. An example of a correlational research could be a study to determine if there is a connection between baby boys with autism and having a father who works for science.

3. Longitudinal study can give us information about how people's behaviors, values, and other variables of study interest change over time. In this type of study, a group of people called a statistical population is studied over a while, and the same behavior is measured several times. The advantage of a longitudinal study is that it allows researchers to record changes and the chronology of the development of the latter. Completing a longitudinal study takes a long time. An example of a longitudinal study could be a study of the same condition of the same children with autism at one point in time, and one year later, to detect changes in the condition.

4. In the context of experimental design, the researcher identifies one or more variables to determine the changes caused by that variable. Experimental studies are often used to determine the effectiveness of a person's medical intervention. There are two groups to be studied – the  control and the experimental groups. It is necessary to ensure the similarity of the two groups, and to trace the effect of the embedded variable during the experiment. That is, all activities are performed in the control group, as in the experimental group, except that the participants in the control group do not receive any intervention (for example, medical intervention). It is important to ensure the stability of both groups and exclude the possible additional influence of external factors. Experimental research allows researchers to study causal links. However, the findings cannot always be generalized to "real" situations. What happens in a controlled study environment can be very different from what can happen in real life, for instance, in a usual classroom.[7] An example of experimental studies is the study of misbehavior of two groups of preschool children with autism. The first group involves those children attending preschool, with whom the work aimed at changing the behavior has been done (there has been an intervention). No work was done with the children of the second group. The research can reveal whether the intervention gave results or not.

A clinical trial is a type of experimental study in which the tests are usually performed in a medical or other clinical settings.

Another type of experimental design is the scientific experiment, which aims to measure the impact of an independent variable (cause) on a dependent variable (result). The main features of the scientific experiment are the control over the variables, the accurate measurement, and the establishment of causal links. To establish causal links, the independent variable is changed, and the change of the dependent variable is measured, that is, what effect it has. During this time, all the other variables (known as extraneous variables) are managed and controlled by the experimental group. There are three main types of scientific experiments: laboratory experiments, field experiments, and comparative experiments. Laboratory experiments are performed under artificially controlled conditions, in an environment such as a laboratory. Field experiments are carried out in real life, for example, at school, in a psychiatric institution or in a care facility. In the case of comparison experiments, societies or groups are compared that are similar in some respects but differ in other characteristics that are also compared. Scientific experiments may be more important in identifying and evidencing discrimination against persons with psychosocial disabilities and/or with mental health problems, considering that the results of the experiments can also be used as evidence of discrimination.

5. In the case of mixed research methods, the most common and well-known type of design is the triangulation design. The purpose of this design is to "obtain different but complementary data on the same problem or phenomenon under study to better understand the research problem."[8] When using this design, you need to combine the strengths and weaknesses of quantitative and qualitative methods. Through parallel operations, this design is used when the researcher wants to directly compare and oppose quantitative statistical results with qualitative findings, or validate or expand on quantitative results with qualitative data. This design is often referred to as simultaneous triangulation design. It usually involves the simultaneous but separate and parallel collection of qualitative and quantitative data and analysis, which helps the researcher to better understand the research problem. In mixed research, embedded design is used as well, in which one data set provides a supportive, secondary role in a study based primarily on the other data type. Since one

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[7] Choosing a mixed methods design, John W. Creswell, Vicki L. Plano Clark. SAGE Publications, c2007. https://www.sagepub.com/sites/default/files/upm-binaries/10982_Chapter_4.pdf

[8] Ibid.

data set is not sufficient, there is a need to find answers to other questions, and the answers to these questions require different types of data. This approach is mainly used in cases when the qualitative data needs to be included in answering the research question during quantitative research.[9]

**The Component of Participation in Research**

One of the ways to ensure the rights of vulnerable groups and the validity of the research on cases and relationships with the involvement of these groups, as well as to reduce the risk of bias, is by ensuring the participation of these groups in research.[10]

The core ideology of participatory research is that the research subjects are involved in the research process as researchers and partners, where the priority is the respect for their knowledge, skills, and experience.

The most important precondition for conducting participatory research is the creation of a "safe space", as participatory research presupposes the willingness of participants to share their views, experiences, and opinions with others, which is possible only in a safe, trustworthy environment.

The following types of participatory research are mainly distinguished: participatory research, participatory action research, and participatory evaluation.

When involving persons with psychosocial disabilities and/or with mental health problems in participatory research, it is necessary to provide accessible means for persons according to their needs, as well as to form expectations from their participation.

It is also required to be ready to respond to the emerging demands and participation needs according to the situation. The following sections of this guide discuss the possible difficulties in ensuring the participation of persons and ways to overcome them.

### 1.2.1 Research Implementation Stages

**The main stages of research are:**

- Preparatory stage, includes generating a research idea and compiling a research project. It involves the development of a video and methodological basis for research. During the preparatory stage, a research action plan is also developed. The research action plan defines the actions, the persons involved, the final outcomes and the deadlines.
- Primary data collection phase or field research, which involves taking measurements using a variety of tools, obtaining the information needed for the research.
- Data processing stage, during which the received data is summarized and verified. This phase may involve different actions depending on the type of research being conducted. In the case of

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[9] Ibid.

[10] See the subchapter “Ethical Issues and Risks of Conducting Research Involving Vulnerable Groups.”

quantitative research, the data are entered in the corresponding programs, through which the data are analyzed, and in the case of qualitative research, the answers to the questions are encoded.

- Results analysis and writing/publishing a statement or a research report. At this stage, the results of the research are analyzed, the problems are identified, suggestions are developed, a statement/research report is prepared and published.

From the beginning of the preparatory stage, there is a need to ensure the involvement of field specialists to understand the specifics and dangers of the field, and conduct research in line with the latter.

## 1.3. Research Project

The components of a research project are:

- Formulation of a research question. Defining the question at which the research is aimed, the answer to which is attempted to be given through the research. It should be clear, concise, and worded so that the audience or the reader can easily understand it without further explanation. It must be measurable, formulated so narrowly that it can be fully studied, clearly defined and brief, expressed in as few words as possible.

- Description of a problematic situation. It is the substantiation of the research problem under study, the background. It also includes information on what research on the issue has been done so far, as well as on problems that have been left open. Data on the urgency of the problem and the factors determining the necessity for research are presented.

- Research problem definition. It is the definition of a question that contains a contradiction between what is known and what is not known, what is defined and what is practical; it is the question the answer to which is given through the research.

- Goal setting. What does the researcher want to achieve through the research? If the research question is the formulation of a problem whose scope is being studied through research, then the purpose of the research is to formulate the obtainment of the answer to that question, i.e., it summarizes the value that the researcher wants to achieve at the end of the research. Depending on the purpose, research can be descriptive, explanatory or exploratory.

- In the case of descriptive research, the purpose of the research is to present the phenomena, situations, and relationships which have not been discussed from this or that point of view. These studies do not answer the question of why something happens or what causes it. However, they can be used to study relationships between variables. It is mainly used at the stage when there is a necessity to formulate hypotheses which have already been tested by other research studies.

- In the case of explanatory research, the causal relations are explained.

- In the case of exploratory research, lesser-known phenomena, subjects and situations are studied. Such research, by giving primary data, mainly becomes the basis for other research studies.

- Object definition. The object is what the research is aimed at. The object also implies from whom the information should be obtained.

- Subject definition. The significant practical and theoretical features, properties, and characteristics of the object are the subject of the study. The subject suggests what about the researcher should get information.
- Problem definition. Problems are the steps to achieving the goal. As a result of exploration, the goals help achieve the goal of the research. Defining the research object and subject helps to identify the applicable methods, which methods are more appropriate, and what limitations these methods have within the framework of the object and the subject being studied.[11]
- Concept definition (basic concepts), which implies:

- Theoretical definition, which provides basic information about the concept under study. For example, according to the theoretical definition of "beneficiary satisfaction", it is the beneficiary's experience concerning the service, depending on the degree to which the beneficiary's expectations are met.

- Operational definition or operationalization: through operationalization, theoretical definitions are transformed into measurable units in reality, which is especially important for justifying the research study. An operational definition is one of the most effective ways to reduce subjectivity and increase reliability.

For operationalization, three main steps need to be taken:

1. to identify the main concepts that are of interest in terms of the study - based on the research interests and goals, to define the topic and formulate a preliminary research question. For example, is there a connection between adolescent sleep and "social media behavior"? Here we can distinguish two main concepts: sleep and behavior on social media.
2. to choose variables that represent each concept - Understand the characteristics and measurable properties of these concepts. In the case of sleep, these can be the quality, the volume, in the case of social media, the forms of social media, the frequency of social media use, etc.
3. to select indicators to measure each variable. Sometimes these indicators can be obvious, for example, sleep deprivation can be represented by the number of night hours. But choosing a sleep quality indicator is more difficult. In this case, we can rely on previous studies. In case it is difficult or impossible to find a suitable study, the researcher can develop the indicators by involving other relevant specialists.[12]

## 1.4. Research Methods

Research methods are strategies and processes used to collect data or analyze information to identify new information or to gain a better understanding of the topic under study.

In research methods, Various research tools are used to help reveal the data on the research interests. Thus, the survey is a method, the questionnaire is a tool, the observation is a method, and the observation card is a tool.

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[11] P. Verschuren, H. Doorewaard Designing a Research Project, 2010, https://www.businezz.nl/media/6/9789059315723_inkijkexemplaar.pdf

[12] Pritha Bhandari, A guide to operationalization,13.08.2021, https://www.scribbr.com/dissertation/operationalization/

It is accepted to separate 3 main methods.

- Survey;
- Observation;
- Document analysis.

**The most common methods of qualitative research are:**

- Qualitative surveys (interview survey, focus group discussion, oral storytelling or life stories, autoethnography);
- Observations;
- Document analysis.

- **The most common methods of quantitative research are:**

- Surveys (questionnaire surveys).
- Observations (if in the case of qualitative research, observations are aimed at the study of place, context, roles and behavior, then in the case of quantitative research, they aim to explore the frequency of repetition of a certain phenomenon).
- Content analysis (used to determine the presence of certain words, topics, or concepts in qualitative data. With content analysis, researchers can quantify and analyze the presence, meaning, and interrelation of such specific words, topics, or concepts.[13]

In the field of psychosocial disability and/or rights of persons with mental health problems, the methods of life stories, case studies and autoethnography are often used to overcome the stigma and ensure representation. The following sections will discuss the specifics of applying survey, monitoring, and document analysis methods. These characteristics also apply to oral storytelling, auto-ethnography or other methods, as in these cases the “toolkit” of surveys, observations and document studies is widely used.

Autoethnography is a form of research that involves self-observation - a reflexive study in the context of ethnographic fieldwork. In conducting research on various visible and invisible disabilities, such as mental health conditions, this method is applicable for presenting the experiences of persons with disabilities from their point of view, for increasing their representation, for making their opinion's/approaches heard. Researcher Polchik notes that autoethnography is a viable method for researchers who have to overcome physical and (or) cultural barriers to disability.[14]

Stories have been used as a research method in various fields, including public health, social work, anthropology, research on understanding marginalized communities, etc. In practice, stories as a research tool can have different dimensions. In recent years, digital storytelling and personal storytelling through audio or video has become more popular.

Storytelling, as a method of qualitative research, is still a developing field and can serve as a supplement to data obtained through more traditional, empirical, qualitative research methods. They can help to

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[13] Qualitative vs quantitative research—what’s the difference, https://bit.ly/3yEIAPj

[14] Polczyk, P. (2012). Autoethnography as an Accessible Method of Research. Forum Oświatowe, 2(47), 175-182 https://core.ac.uk/download/pdf/51278858.pdf

understand the nuances of people's experiences, which may be inaccessible when using more advanced research methods. Moreover, stories do not bring to light exceptionally one, the only revealed truth, because the truth is a matter of a certain degree of perspective. The combined use of traditional research methods with stories can provide more in-depth and insightful information about people's experiences.

### 1.4.1 Survey Method

The survey method uses questions as a tool for recognizing social reality. The survey method types are the interview and the questionnaire surveys.

**There are three stages of survey:**

1. Preparatory - the stage of establishing a secure, trusting relationship between the respondent and the interviewer?
2. Basic - The main questions that can be asked from the research point of view are asked.
3. Tension relief or closing – the recovery of respondent’s emotional state, the stage of eliminating the negative emotional background, the relief of the tension caused by the survey and establishing the same emotional state of the respondent as it was before the survey.

Surveys can be conducted remotely or face-to-face. They can be implemented through structured or unstructured questionnaires and interviews. A remote survey, when the questionnaire is sent to the respondent to fill in, requires fewer resources, including time from the researcher, but if it is used, the representation of the sample is endangered, and the feedback is low. In recent years, the ability to conduct remote interviews via video or voice communication has evolved.

**Survey questionnaire**

In the case of a questionnaire, the pre-formulated questionnaire is given to the respondent to fill in, after which he/she returns the questionnaire to the interviewer.

The questionnaire starts with introductory information, which includes the research goal, information about the researcher, the procedure for answering the questions, the thank-you note for participation, and the text of the informed consent. The questions in the questionnaire should be written in simple words, avoiding ambiguities as much as possible. The sequence of questions has the following logic: simple questions, difficult questions, and simple questions. The questionnaire should not start with questions that may repel the respondent, just as it should not end with difficult questions. The questionnaire can have thematic sections, for example, questions related to the field of health can be presented in a separate section, questions from the field of education – in another section, etc.  The transition between sections should not be too abrupt. The questions should evolve from one another.

The types of questions included in the questionnaire are:

- Closed-ended questions – where all possible answers are presented, and the respondent must choose one of the options. These questions are more likely to get clear answers. Developing closed-ended questions is easier for the researcher.

- Open-ended questions - these do not imply the existence of response options. After the question, open space is provided to answer it. Although these questions provide an opportunity to receive unique answers in terms of content, they are more difficult in terms of data analysis. In addition, there is a risk that the respondent will not want to answer open-ended questions due to lack of time or other reasons. From the point of view of making the data analysis process easier, the formulation of questions is especially important.

- Semi-closed or semi-open questions - where the main answers are mentioned, but at the end space is provided for an option for the respondents to express their point of view.

It is important to make sure that the questions are worded clearly, so that they are perceived by the respondents unambiguously, as well as they assume answers in the same dimension. As a rule, most of the inaccuracies come from question formulation.[15]

Questions should be formed neutrally and should not contain hints or tips.

## Interview Surveys

An interview is different from a regular conversation. Although the interview is similar to the conversation, as both have verbal (oral) and non-verbal (written) communication, during which there is an exchange of views, the main difference is that the interview is aimed at achieving a consciously chosen goal.

In the case of interviews, the rate of return on responses is higher. On the other hand, the interviewer's identity, behavior, gender, nationality, clothing, and other factors may affect the respondent's answers, as it is more difficult to guarantee the anonymity of the answers, thus, the respondent may have more fears of answering freely.

Some of the factors of the interview effectiveness are:

- The place of the interview should not be overwhelming. It is necessary to exclude or reduce external factors that may adversely affect the sincerity of the respondent's answers. For example, if the interview is conducted in a place to which other people have access, the respondent may be afraid that their answers will be heard, which will make it difficult for them. Or if the interview is conducted at an institution and one of the employees has the opportunity to interrupt the process, this can also be a constraining factor. It is necessary to choose a place where the respondent will feel calm and safe.
- Criticism should be ruled out and a safe environment should be created in which the respondent will not have to worry about being criticized for his/her answers.
- Do not ask questions that are of the interviewer's interest and are not related to the survey. This does not refer to the questions asked during the interview, which aim to create an atmosphere of trust, in some cases, to address the interviewee’s resistance.

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[15] S. Farrell Open-Ended vs. Closed-Ended Questions in User, 22.05.2016 https://bit.ly/3283muY

- After a question is asked, the respondent should be given time to think. It is necessary to take into account the respondent’s speed of analysis and to conduct the interview in a way convenient for the respondent.
- You should not use concepts that the interviewee will not understand.

**Interview types**

Depending on the degree of standardization, the interview can be unstructured, semi-structured and structured.

- In the case of an unstructured or free interview, there are no pre-formulated questions. There is only a thematic direction. In this case, the interview plan is made, and the main directions around which the interview will be conducted are defined. The effectiveness of the interview greatly depends on the skills and training of the interviewer.
- Closed-ended questions are used for structured interviews.
- In the case of a semi-structured interview, all the three types of interviews (open-ended, closed-ended and semi-closed / semi-open questions) can be used together, or any combination of two types of interviews can be chosen.

Two types of surveys may be distinguished - individual and group. In the case of individual surveys, there is only one respondent, and in the case of a group survey, the information is collected from a group of people interviewed at the same time, and the answers immerge as a result of discussions based on the respondents’ experiences, by associations. An example of such an interview is the focus group discussion.

Some researchers emphasize the applicability of dyadic interviews to ensure the participation of the most vulnerable persons, particularly those with mental health problems. A dyadic interview means interviewing two participants simultaneously. This interview method acknowledges that the two individuals are interdependent, and tries to use this relationship as a source of information.

Although the dyadic approach was considered a method of triangulation for many years, it was later used as a means of ensuring accessibility for persons with mental health problems and was adapted to promote the participation of the latter. The dyad, the group of respondents, in this case, as a rule, consists of a person with mental health problems, and a person whom he chooses as a main supporter.

A dyadic interview is a methodology of interconnectedness, because instead of ignoring and controlling the seeming independence among people, in this case, a person with mental health problems and his/her supporter, it recognizes the value of interconnected relationships, and interprets them in such a way that the will and preferences of the person with mental health problems are kept in the center of attention. Moreover, it helps not to have unrealistic expectations from persons with mental health problems, i.e. that they will "be able" to participate in the interview without support. A dyadic interview is based on the opportunity for the person with mental health problems to make a choice. This does not mean that the person cannot ask the supporter to decide for him/her, but it means that the decision that has been made is a manifestation of that person's autonomy. However, it is necessary to take into account that when conducting a joint interview, there will most likely be an imbalance of power, and the supporter will prevail during the interview. Caldwell suggests using a special dyadic interview procedure for people with mental health problems that will reduce the risk of power imbalance and the dominance of supportive approaches over the opinion of a person with mental health problems. Instead of conducting a joint interview, he suggests the following procedure:

1. The researcher conducts a separate interview with the participant on the topic.
2. The researcher then meets with the supporter separately, and interviews him/her on the same topic, gathering additional information.
3. Conducts a final interview with the participant separately, using the questions formed as a result of the previous two interviews to gather additional information on the case/experience under study.

An expert survey and a key informant survey are types of surveys.

In the case of expert interviews, experts are seen as expressing a collective opinion, as if "conveying", coordinating the views of a large number of other people. Expert interviews are also used in situations where a particular location or problem-solver is difficult or inaccessible, such as in closed institutions or on taboo topics. The expert survey can be used in the preliminary exploration stage, and the data obtained can be used as a basis for the preparation of research tools, which helps to get the necessary basic information in advance and to start the fieldwork more preparedly. The level of knowledge of the respondent in the field is key in an expert survey. Issues related to criteria for being considered an expert, the definition of expert knowledge, and being considered a "good" or "bad" expert should be discussed.[16]

In the case of a key informant survey, the respondent is a person who has "first-hand" knowledge on the topic under study. For example, in the case of community-based research, the community leader may be considered a key informant because he or she is aware of what is happening and what processes are going on in the community. Key informants are not experts, but they have valuable information on a topic of interest for research.

## The Use of Interviews and Surveys in Conducting Research Involving Persons with Psychosocial Disabilities and/or Mental Health Problems

Persons with psychosocial disabilities and/or mental health problems are as diverse as persons without disabilities. They may have very different needs, so no manual or guideline can offer solutions to all situations. In case of difficulty, the respondent can be asked how he/she prefers to listen to the questions or how it is clearer for him/her. The person knows that answer best, and the approaches of the researcher and the interviewer are assumptions based on the experiences of other people and other researchers. Below are some general considerations.

### Preparatory Work

*Place and Time of the Interview*

Before the interview, it is necessary to choose the place and time that is convenient for both the researcher and the interviewer.

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[16] UCLA Center for Health Policy ResearchKey Informant Interviews https://healthpolicy.ucla.edu/programs/health-data/trainings/Documents/tw_cba23.pdf

Preference may be given to places with which the researcher is familiar, the conditions (privacy opportunities, lighting, heating or cooling conditions, noise, etc.) of which he is well aware of. At the same time, the respondent's preferences may not be ignored.

If the respondent’s preferred location is chosen, make sure that the room is technically equipped (for example, there are sockets for rechargeable devices) and can offer secluded conditions. If the respondent invites you to his/her house, this is a good sign, but the researcher should make sure that he/she will feel comfortable and safe in such a place. Whenever possible, places where the respondent will be with children (or pets) or people under their care should be avoided.  It is necessary to make sure that there are no people in the area who can impact the respondents' answers. It is necessary to agree in advance on the involvement of a personal assistant or translator.

In case an unfamiliar site is chosen, for security reasons, the researcher should inform a trusted person, a family member, or a colleague in advance about the location of the interview. It is possible to agree on what action to take in case of not returning at a specific time or in case of unavailability. It is probable to have an additional phone, charger, and activated telephone internet connection.

It is necessary to agree in advance on how long the interview will take. This can help alleviate the anxiety of persons with mental health problems, plan their day or take medication.

Before the interview, it is advisable to remind the respondent in an accessible way about the location of the interview and the interviewer’s contact information, which will be especially helpful when the person has memory or orientation difficulties.

### *The Choice of Communication Form*

The interviewer should find out in advance what the difficulties of communication with his "respondent" can be. For example, a person's speech may be difficult for strangers to understand. The possibility of using other forms of communication can be discussed, communicating by writing on paper, drawing, using a computer keyboard, etc. Another option is the participation of one of the family members or some other trusted person. In this case, it should be taken into account that if the information is provided by the mediator, the latter may express not the respondent’s direct speech, but his/her own comment. Therefore, it is needed to talk to the mediator in advance, to explain why it is essential to convey the respondent’s verbatim speech, and not the general idea. The same can be said when a person communicates in sign language or other unfamiliar languages. In case of a need for a translator involvement, it is necessary to talk to them in advance, to present the research study and the main terms used. The accuracy of translation is of paramount importance, and translators can sometimes reformulate the message, while the researcher will not be aware of such changes. When communicating with a respondent in the presence of/or through a mediator, it is important to remember that eye contact should be maintained with the respondent and not with the mediator.

### *Request for Informed Consent*

When requesting a prior consent, it is necessary to inform about the topic of the interview. The purpose of the research should be presented to the respondent. Goal setting allows the respondent to form clear expectations of what they and the research will gain from their participation. It is necessary to inform in advance that if there are questions that the person does not want to answer, he/she has the option not to do so.

It is also necessary to obtain the consent of the respondent to publish his data within the frame of the research. However, even when the respondent agrees, the researcher may decide not to publish the data due to possible risks. The respondent should be informed that if he/she does not want to, the interview information will not be published in a way that the respondent may be identified. This can especially help to create a safe environment when conducting research with persons with psychosocial disabilities and/or persons with mental health problems in institutions or dependent on other people.

If the researcher decides that he/she will request informed consent from the respondent in writing, the informed consent form must be printed in advance. The form should contain the information needed to obtain informed consent, i.e. basic information about the research, including the benefits and the harms. A written informed consent form may be replaced by electronic tools that can convey the same information in verbal form. It is important to ensure that the information contained in the informed consent, both in electronic and paper versions, is provided to the individual in an accessible way and with accessible content. For more data on informed consent, including data provided for obtaining informed consent, see chapter 3.1. "Legal Issues in Conducting Research".

## Implementation Stage

### *Formulation of Questions*

When formulating questions, it is necessary to keep in mind that some persons with psychosocial disabilities and/or mental health problems may have difficulty talking about abstract concepts. Therefore, the questions should be formulated as simply as possible, using specific concepts. For example, questions about time or numbers can be problematic, so questions such as "how much", "how often" or "when" can be avoided. We should avoid expressions, phrases, and ambiguous words that have a figurative meaning.
Sentences should be short, and each sentence should address only one topic.

It is preferable to avoid questions that can be answered with "yes" or "no". In case of receiving "yes" or "no" answers, more specific questions may follow, such as "Why do you think so?", "How will you substantiate your answer", "Could you go into details a little more", etc.

The interviewer may use some expressions such as "I understand", "go on", "yes, good", etc. You can also use non-verbal forms - "nod", "lean forward", and "smile", that help the respondent to feel understood and to continue speaking, but this form is not applicable when the respondent has visual impairments. If the answer is not clear, the interviewer can ask clarifying questions to find out if he or she understood the answer, such as "You say that…", "Do you mean that…", "As I understood…", etc.

People with mental health problems compared to the general population are more likely to answer questions in a way the respondent thinks the interviewer would like to hear. This problem can be overcome by formulating as simple questions as possible. In addition, the interviewer should alleviate the respondent's anxiety as much as possible. Depending on the situation, the interviewer should be ready, for example, to drink tea or coffee with the respondent or their family members. The interviewer should be perceived as friendly or at least neutral to the respondent.

If during the answer to a question the respondent is excited, and the interviewer feels that he/she will not be able to control the process, they can refer to the question when the respondent was feeling calm and was having positive feelings.

It should be noted that a person may give different answers to the same question or not answer open-ended questions. In such cases, situational solutions may be best. You can try to get the necessary information through closed-ended questions, but you need to be careful not to be guided by those questions. You can move on to another question and return to the former question later.

In the case of questionnaires or surveys, respondents may always choose the last or the last but one option if it is a question of multiple-choice or enumerated answers. One reason may be that one may forget the answers given at the beginning. In case of such doubts, the question can be reformed, and the places of the answers can be changed. Another way is to get the general picture by answering with "yes" or "no". It is possible to prepare response cards in advance, through the choice of which the respondent will answer the questions.

### *Use of Pictures During the Interview*

Picture cards can be used during the interview. They can make the conversation either complicated or simplified. By showing a situation card, the interviewer can describe it and formulate the question. For example, it is a card depicting violence, followed by a question like what the abused person should do in this case. If a person has ever been in such a situation, he/she can tell more freely about his experience. Such mechanisms can increase the efficiency of data collection.

Pictures can help not only to form questions, but also to answer them. The respondent can be asked to express his / her opinion through drawing if the person does not communicate in verbal form. For instance, children or some persons with mental problems who are unable to or have difficulty in expressing their thoughts in verbal form, can draw. Pictures can help the researcher obtain data and can be the main method of research.

For work with respondents who communicate through pictures, we may involve specialists knowing alternative communication systems. One of such tools is Picture Exchange Communication System better known as PECS. This way, specialists can help ask questions and get the answers through pictures.

### *Interviewing by a Specialist*

Another way of interviewing is by a psychologist or other specialist, or in specially furnished rooms, where the interview is observed also by other specialists behind the one-sided mirror. The method is often used in interviews with children. When conducting interviews in specially furnished rooms, it is important to inform the person, including the child, that there is a room behind the mirror, to inform who will be following the conversation. The respondent can go to the other side of the room to get acquainted with the environment and the people by option. This means is mostly used when, in addition to the main interviewer, there is a need to involve other professionals who, for example, will follow the respondent’s non-verbal behavior. This technique is rarely used in in-depth interviews, usually it is used in clinical or psychological observations.

### *Interview Recording*

During structured or semi-structured interviews, interviewers can write down the answers as accurately as possible. For unstructured interviews, interviewers often record the discussion rather than try to write it down.

When recording or videotaping interviews, it is necessary to obtain the informed consent of the respondent. The intervier should also remember that the recording may make the respondent feel uncomfortable, even if he/she has given his/her consent.

## Focus Group Discussion

### Preparatory Stage

Focus group discussions are often used as a research method when researching the rights of people with psychosocial disabilities and/or mental health problems or in case of the participation of the latter in the research study. The reason is that focus groups allow one to listen to many opinions, suggestions and ideas, understand personal experiences and study various issues in depth.

Focus groups provide detailed qualitative data based on group communication, which are inductive, about the group members' perceptions, thoughts, feelings, and impressions, based on the group's and participants’ experiences and are presented in their words.

For the cases of respondent’s participation in a focus group discussion in the presence or with the support of a mediator, see also the subtitle " The Choice of Communication Form" under subchapter 1.4.1 " Survey Method " of the Guide.

*Sample, number of focus group participants*
When planning a focus group discussion, it is first necessary to identify who the participants will be. They can be selected according to the general geographical area, services received, and general experiences, for example, people who have the same concerns about psychotropic drugs.

There are two types of groups: **general consolidation** and **sample consolidation**. The bearers of the issue form the **general consolidation**, and the percentage of the people who will take part in the research forms the **sample consolidation**. The sample consolidation cannot be outside the general consolidation. The sample consolidation maximum represents the general consolidation, both in terms of structure and properties. All elements of the general consolidation should have the opportunity to appear in the sample consolidation, which is one of the strongest grounds for representation. The sampling is carried out through special techniques and formulas, taking into account some indicators, such as the size and structure of the general consolidation group, the desired degree of validity, and the degree of permissible deviation.

Groups can be formed by a simple random sampling, you can turn to different people and ask them to participate in a focus group discussion. Participants can alsoo be involved by the "avalanche" method when the researcher selects one participant and the latter invites other people. Another method is to join groups that have already been formed, for example, to invite a committee to participate in the study.

Obtaining data can help to form groups by sending questionnaires to potential participants in advance. Through this, it is possible to get the initial positions of the participants on the topic, as well as general (socio-demographic) data about them. This will help to create groups that have the right balance. Participants' communication or other needs that may prevent them from completing the questionnaire should be considered. This in itself should not prevent a person from engaging in a focus group discussion.

The group can ensure the diversity of participants' views and experiences. When participants from the same group have the same or slightly different positions, it reduces the opportunity to get different data and a comprehensive overview.

At best, there should be at least six participants in each focus group, but this does not mean that large groups are less effective. It should be borne in mind that if the groups are large, persons with mental health problems may find it difficult to participate in the discussions. Difficulties and fears of speaking in large groups are natural and common to many. Large groups can also impede a person's participation when he/she has difficulty hearing or speaking.

In any case, when determining the size of the groups, researchers should be guided by the principle of the participants’ comfort. The effectiveness of a large group depends not only on the cognitive abilities of the participants, but also on the environment and the skills of the moderator.

Whenever possible, more than 20% of the total number of participants should be invited to the discussion. It should be taken into account that usually not all participants can attend.

Encouraging mechanisms are sometimes used to promote human participation. For example, researchers reimburse the person’s transportation expenses, donate a book, or offer an opportunity to attend some courses. However, this should be done in a balanced way, because such measures can affect the objectivity of the respondent’s answers. Participation is facilitated when coffee breaks or other meals are planned in parallel with the discussion, especially when it takes place at lunch or dinner time. Care must be taken for such funds not to be considered by participants as charity or a fee for participation.

### *The Venue of the Focus Group Discussion*

When choosing a location for the focus group discussion, it is advisable to choose an area that is frequently visited by the participants. When deciding on a day and time, you can be guided by the principles of the participants' habits or choose a convenient time for them. This will make it easier for people to participate, to build trust between the researcher and the participants. It should be kept in mind that the environment can impact the answers, so you should avoid places where people may be constrained to speak on a chosen topic.

It is necessary to provide sufficient lighting, ventilation, and temperature in the room. The direct rays of the sun can interfere, and poor lighting can be just as disruptive.

We must make sure that the area is not noisy and is isolated. To ensure silence, the note "Do not enter" can be posted on the door of the room.

When choosing an area, its accessibility for people with mobility difficulties should be taken into account. Not only the entrance but also the bathroom should be accessible, the doors should be wide enough, it should be possible to easily approach the tables, enjoy the hospitality, etc. The environment should be such that all participants feel involved. Such an environment can also reduce participants' anxiety.

Focus group participants should be asked in advance if they need reasonable accomidations. For example, if you plan to distribute printed materials, you may need them in Braille or large print. Or participants may need a sign language interpreter because of a hearing problem.

Persons with psychosocial disabilities and/or with mental health problems may need a help of an assistant or a mentor. Such an option should not be rejected, it is possible to participate not only directly, but also with the support of everyone.

A day or a few hours before the discussion, participants may be reminded of the discussion, which will help them not to forget about the meeting. Participants should be given the interviewer's contact details in advance.

### *Focus Group Discussion Recording*

During the discussion, the data can be video/audio-typed  or written down. If the researcher is not going to video/audio-type the discussion or has not received the participants' consent on doing so, he/she can  use the pair-work approach, when one is conducting the discussion and the other is taking notes. Regardless of whether you are video/audio-typing or taking notes, it is helpful to write down your notes, observations, and analytical thoughts immediately after the interview or discussion. If the researcher wants to record the meeting, he/she must inform the participants in advance and get their informed consent. The researcher must guarantee confidentiality and that the recording will not be passed on to other persons, or inform them to whom it may be passed. Participants can be asked to introduce themselves in advance, this will help identify the person's voice when transcribing.

It is necessary to make sure in advance that the recorder is charged and has enough memory. You need to make sure that the voice will be audible for recording anywhere you speak from.

In the case of taking photos, it is necessary to get the consent of the participants and to inform them for what purpose the photos will be used.

Participants should be confident that all the information they provide will be kept confidential by researchers, and they should be free not to disclose any information they do not wish to disclose. For this purpose, no one may enter the room during the discussion, the discussion should not be held in an open area where other people are sitting nearby.

It is necessary to develop an informed consent form in advance, to present it to the participants in verbal form and in simple words.

For details on informed consent and participants' personal data protection, see chapter 3.1. "Legal issues in Research."

## **Implementation Stage**

### *The Discussion Process*

It is necessary to have a discussion agenda. One must avoid starting the meeting early and avoid any deviations from the agenda. Before starting, you can just get acquainted with the participants, and communicate informally with them. Short conversations can help to overcome tension. The participants should be presented with the main topic of discussion beforehand. It will help to think in advance in that direction, to formulate the thoughts. First of all, you can thank the participants, ask them to introduce themselves, then you should present the topic to be discussed, the purpose of the research, the basic rules of the discussion, and afterwards start asking the first question.

During the discussion, there may be no pauses, the questions should not be exhausted ahead of time. However, planning a break may be helpful when participants are tired or may need to use the bathroom.

On the other hand, the break can interrupt the communication between the participants, and slow down the process, so it is good to have water or juice on the table from the very beginning, especially when the discussion will last more than an hour.

It is necessary to set basic rules at the beginning of the focus group discussion. For example, the principle of not interrupting, the principle of not passing information heard about each other to other people. It may be highlighted from the start that if a person disagrees with someone's opinion, he/she may later express his / her own opinion.

### *Conducting a Discussion and Formulating Questions*

Questions should be formulated briefly and clearly, and be easily understood by all participants. The questions can be grouped by topic, with two to six questions on each topic. Before the questions, each topic should be presented to the participants so that it is clear what the upcoming questions will be about. If any additional questions arise in the process, they can be addressed after completing the group of questions so that the discussion process is not disrupted.

As a rule, the questions are formulated by the principle of going from the general to the private ones. For example:

Question 1. What do you think about the services provided for you?

Question 2: In your opinion, which part of these services is well provided and which part is provided poorly?

Visual materials can be used to simplify the questions. For example, images of incomprehensible nouns. You can use cards with the colors of the traffic light to give their meanings. For example, red may mean "I do not understand" or "no", orange - "say slowly" or "repeat", and green cards - "yes" or "I understand".

One should remember that the role of the moderator is not to change the opinion of the group members, to inform or educate them, but to listen and record their opinions. The moderator must control his / her emotions. We should remember that dispositions or bias can be expressed through verbal or non-verbal reactions to the participants' statements, for example, by expressing surprise. One should be ready to listen to relevant and irrelevant answers, questions and observations. The focus group moderator should emphasize that there are no right or wrong answers. It is necessary to ensure that the participants speak in turns to avoid noise.

The moderator should speak slowly and clearly, allowing the participants to think before answering.

The moderator should prevent interruptions by allowing participants to make additions after others’ speech, rather than interrupting another participant who is already speaking.

People who use the services being studied should be reminded that researchers do not work for any organization rendering these services. If not, the participants should be aware of the impact that their participation may have on the services they use.

There may be people in the group who want to answer all of the moderator's questions. You should also pay attention to the non-verbal behavior of other participants, and invite them to participate in the discussion, for example, by saying, "You seem to nod your head, do you agree with that?" This will allow more silent participants to be part of the discussion.

You should try to look for commonalities and differences in opinions. They will ensure the smooth course of the discussion.

When one participant is speaking, you can study other participants' reactions to see if there is agreement or disagreement, if it is not clear from their non-verbal expressions, ask the other members of the group if they agree or disagree with the comment.

If someone is participating in the discussion with a companion, assistant, or translator, care should be taken to talk to the person with a psychosocial disabilities and/or with mental health problems, rather than their companion, assistant, or translator.

Various additional techniques can be used during the discussion, including voting tools, videos, flipcharts, etc. They may facilitate the discussion, but it should be kept in mind that some tools, such as flipcharts, can give the impression of teaching rather than discussing.

Make sure that all participants have the opportunity to summarize their dispositions at the end of the focus group discussion, as well as ask any questions they may have.

You may suggest to send the research findings to the participants in case of interest. For this purpose, it is necessary to have the contact details of the participants.

It is of atmost importance to thank the participants for their participation and efforts.

If someone needs to speak out after the discussion, the moderator should listen to him/her, but he/she should be careful not to advise on the issues raised, especially if he/she does not have enough information. If the person needs additional support, they can be given contact details of trustworthy professionals and NGOs.

*Data Processing after Focus Group Discussion*

When the focus group discussion is completed, it is important to immediately transcribe and analyze the data received. The analysis is performed based onb transcription, recording, notes, and data stored in memory.

Speech may not be corrected, including grammar, pronunciation, and other characteristics such as laughter and head movement recorded by notes or recordings. In case it is not possible to identify who the speaker is based on the recording, it should be marked as "unknown", writing down the presumed gender of the speaker and other characteristics of the speech.

The analytic work should be equally coordinated. One should take care that the final text reflects the views of all participants.

If it is decided that the transcript should be sent for clarification to some participants, it should be borne in mind that they may have changed their minds about their emotional or overly honest responses. When quoting, it is important to remember that quotes are often a part of discussion between two people, so sometimes quoting one person's comments and excluding the other person's comment may render the quote meaningless. In that case, one should not avoid quoting the conversation of two people.

### 1.4.2 Observations

Observation is the direct and immediate recording of information by a researcher about an observation site or observation object right at the scene of events.

The observation method allows obtaining information about the object and the environment.

During the observation, three main components can be studied: the observation area, the actors, and the actions.

The following should be considered in advance:

- The choice of observation type;
- The ability to enter the observation area; and
- The cultural peculiarities and the observation compliance with that culture.

An observation plan or an observation card is drawn up for the observation, which indicates the date, period, place, and data to be collected. It is determined in advance what will be observed, and on what basis (examples of bases can be the standards of living conditions in psychiatric institutions defined by law or international standards).

*Types of* Observation

Based on the observer's involvment, the following types of observations are distinguished:

- participant observation, when the observer participates in the group's activities; and
- non-participant observation, when the observer does not participate in the group's activities; the observation is carried out "from outside."

In the case of participant observation, when the researcher becomes part of the culture or the study context, he/she needs to be accepted in that group in order to succeed.

Based on participants' awareness of the observation, the following types of observations are distinguished:

- undisguised observations, when participants are aware that they are being studied – observed; and
- disguised observations, when participants are not aware that they are being studied – observed.

Based on their frequency, the following types of observations are distinguished:

- regular, when the observation is carried out at certain predetermined intervals for a certain period of time; and
- random, when the observation is carried out based on need or when the exploratory research study did not include it, but in the process, it becomes clear that the observation of the situation is necessary.

## Observation in Organizations Providing Services for Persons with Psychosocial Disabilities and/or Mental Health Problems

The observation of participants is a qualitative method with ethnographic research roots aiming at helping researchers understand the views and behaviors of the population being studied.[17]
Individuals conducting qualitative research use this method both as a main method and in combination with other methods, to study the daily activities of groups of people at different levels. This observation takes place under the usual conditions of the study group, in places that are supposed to have some relevance to the research questions. The method differs from other methods in that the researcher goes to the study environment, instead of participants coming to the researcher. Laboratory observations may be an exception when the observation is carried out in a controlled environment. In general, the researchers engaged in observations of participants' with the aim of trying to understand what life is like for the members of the given group - the "insiders", inevitably remain the "outsider", a stranger.
Understanding people's experiences allows us to assess whether policies are being implemented in practice in the same way as intended, whether there are unintended impacts that need to be addressed, and whether there are issues that remain open.
The study of the experiences of persons using mental health, psychiatric and care services is mainly carried out through an interview or a questionnaire. However, it is not always possible to implement those, no matter how much effort is made to ensure accessibility. For example, some people with dementia may not be able to answer the researcher's questions. In this case, mediators come to the rescue - people who share a person's daily life, however, when talking about subjective reality, they cannot replace the person, because views are formed based on the person's experience, which is not transferable. In this case, the method of observations of participants comes to replace or supplement the other methods.

Although observational research is especially useful when working with people who would not otherwise be able to participate in the research, it can be a useful approach even when individuals can be interviewed.

People with psychosocial disabilities and/or mental health problems may be reluctant to provide information during interviews that they believe may be negative or critical of the service provider. In some cases, they have very low expectations of the service, so in all cases they may say that the support is sufficient, and the quality is satisfactory. The data obtained from observation can show that a person, for example, is dissatisfied with the services or some of them, and then show the weaknesses and limitations of the service that users have not reported.

Researchers on disability issues use this method mainly to study the state of living conditions and realization of rights of people living in institutions or other places of residence. The results of observations largely depend on the subjective perceptions of the observer; the conclusions may not always correspond to reality. Therefore, the observer can record the facts and present the assumptions and conclusions as such.

## Preparatory Work

### *Determining the Observation Time and Location*

The listing of observation locations can be done immediately after clarifying the purpose of the survey. These may be places where the study group attends more frequently. For information about these places, you can

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[17] Iacono, Jessica & Brown, Ann & Holtham, Clive. (2009). Research Methods–a Case Example of Participant Observation. The Electronic Journal of Business Research Methods Volume. 7. 39-46.
https://www.researchgate.net/publication/228365089_Research_Methods-a_Case_Example_of_Participant_Observation
Brancati, Dawn. (2018). Social Scientific Research (London: Sage, 2018).
https://www.researchgate.net/publication/326398608_Social_Scientific_Research_London_Sage_2018

consult with those who use these services, industry experts, or people who work with users of the services. These places can be very different in nature: medical centers, day care organizations, psychological centers, clubs, religious organizations, community meeting places. If topics are considered that involve high risk, for example, issues of sexual violence, then it may be necessary to consider the places where, according to the preliminary assessment, such cases are more likely to be registered.

When approving the methodology, it should be taken into account at what stage the observation is carried out. In some cases, this can be done at the beginning of the data collection stage, but sometimes it can be done during or at the end to address issues raised by other methods. In the process of decision, the period specific to the behavior to be examined must also be taken into account. For example, if the research is related to people applying for medical centers, it should be borne in mind that some diseases may have different manifestations at different times of the year, increasing or decreasing the number of people applying.

### *Observation Team-Building*

The researcher must decide in advance whether to carry out the observations alone or in a team. When making such a decision, the characteristics(such as age, gender, physical appearance, ethnicity, individual language skills, etc)  of the members of the group subject for study, as well as the data collectors should be considered. It will help to organize the work as appropriate.
The team-building of observers and the training of team members can be done immediately after clarifying the research question. Observers should work under proper supervision to ensure that they record the situation and behavior accurately, defined by the methodology developed.

When conducting observations by a team, division of labor can be made. For example, in the case of observations in care institutions, it is possible to divide the groups according to priorities and decide who and in which type of institution ( for children, for the elderly, etc.) should conduct the observation or at one institution, who will visit certain locations.

## Implementation Stage

### *Observation Implementation*

Observations are carried out according to a pre-designed observation cards. In addition to the research question, the following should be considered when conducting observations:

- the appearance of people: clothing, age, gender, other physical properties;
- verbal behavior and relationships: who is talking to whom, how long, who is initiating the communication, what language or language style they are using, tone of voice, etc.;
- behavior and gestures: what do they do, who does what, who is not involved in general activities, etc.;
- flow: who enters the room, how much time they spend in the observation location, etc..

It is not allowed to commit illegal, unauthorized, or sexual acts with the participants of the study. Risks should be considered when engaging in controversial activities, such as drinking alcohol.
The observer should be prepared to respond to uncontrollable situations, including adapting to a variety of conditions, such as noise and emotional distress.
The researcher must be able to control his behavior. For example, when it comes to research that assesses the impact of an intervention, as in the case of experimental design, the researcher should be able to avoid interfering with different activities and letting events take place as they would without the researcher's

presence. To control his/her behavior, the researcher can test his/her abilities in advance through various exercises, and prepare psychologically.

*Observation Recording*

The fieldwork notebook or the observation card can be filled in openly or unnoticed, depending on the situation. In that notebook and / or the observation card, in adherence with the pre-determined methodology, all the data should be filled in - the hours, the concrete location, the people’s actions and other details.

The notes in the notebook and/or the observation card should start with the general data: the date, the location, the area being observed.

The notebook and/or the observation card should be used systematically. It is desirable to leave space for additional notes on each page. It may be helpful to use abbreviations when making notes, but not ones that are difficult to remember or understand later. A list of abbreviations can be made. The structure of the page should allow the reader to easily understand which part of the data is described in certain parts.

Sketches that will depict, for example, the gathering places of people in the institution, the map of the given place, etc. can help record the situations observed.

Situations may occur, where the researcher's participation is needed to better understand the phenomenon, but their presence should not be noticeable.

One way to achieve this is for the researcher to behave like the people around them, for instance, to pray with others in a religious place. This also helps to be aware of the meanings of certain body language (e.g., positions and gestures), as well as the nuances of voice and tone. Under such conditions, it is possible to get acquainted in advance with the cultural and other peculiarities of the place and the group that will presumably be revealed.

While filling in the notebook, you should keep in mind the security guarantees, especially if there is data that could harm the group being observed and allow the individuals to be identified. It should be remembered that the notebook can fall into the hands of other people, so it can endanger both the researcher and the observed group. Depending on the risks, the observation can be encrypted. For example, if it is a closed gathering where the behavior of five acquaintances will be observed, then the option of pseudonyms can be used.

If the behavior of people with mental health problems is to be considered, it is advisable to use a set of codes that define different types of behavior: self-stimulation, self-harm, aggression, property damage, and so on.

When making observations, one should try to describe the factual reality in as measurable formulations as possible, rather than by using general descriptions.

For example, when describing the common room at an institution, the comment might be, "it is dirty and too crowded." The objective description will be: "there are food scraps in all corners of the room, about 25-30 people are gathered, all patients, it is difficult to move around, the size of the room is about 40 square meters."

When taking notes on a situation, one should write down not one’s impressions or expectations, but about what one actually sees. However, impressions, being also valuable, can be documented in a separate comment.

The principle of neutrality should also be kept in mind. To this end, it will be useful for researchers to occasionally ask themselves what evidence they have for this or that assertion.

A camera or a cell-phone can be used to record facts during the observation. The photo will allow us to present  the reality in a visual form. At the same time, the protection of the personal data of the persons being observed should be born in mind and should not be violated. If a phenomenon or an object is being observed, the real syzes of which will be difficult to estimate based on the photo, you may take a picture of it together with some other object the size of which is popular or is presented on it,for example, when photographing the  injuries on the observed person’s body parts, the furniture, the tools or other objects.
Photographs, videotapes and/or audio tapes obtained without the express consent of the individuals and identifying the individuals involved and disclosing any personal data are not acceptable because they violate the Code of Ethics and the Principle of Obtaining informed consent.

### After Conducting Observations

Immediately after the implementation of observations, it is important to proceed to the task of formulating the notes into complete sentences, grouping the general data and  giving their detailed description. If the observation was carried out in the evening, it is advisable to plan the work for the next morning, in order for the details not to be forgotten and for the notes to be still understandable. You should try to complete the records as soon as possible to reduce the risk of information loss.

Other professionals can be involved to help group, summarize, and analyze data. For example, people who are familiar with the area and have mapping skills so that more accurate data from the sketch may be solicited. The ethical principles and the responsibilities for Personal data protection applicable to the core observation  team also apply to the experts partially or fully involved in this stage.

It is important to digitize the notebook. Enter all the texts in the electronic document, and scan the images.

It will be useful to store the data on two different media so that in case of damage to one of them the result of the work will be saved.

## 1.4.3. Document Analysis

Document analysis is a form or a method of qualitative research that uses a regular document analysis procedure to answer a research question. It involves regular study, examination, and interpretation of data to gain empirical knowledge or meaning. It can be used as an independent method or to triangulate findings from other sources (e.g., interviews, focus group discussion transcripts). To this end, document analysis helps to double-check prejudices, including in  the field of mental health.

Primary and/or secondary data are analyzed as part of the document analysis. Primary data provide first-hand information on situations and relationships, without comment and analysis. Examples of primary data are the minutes of a court session, a photo and an advertisement text. Secondary data are the information that is compiled as a result of the analysis and interpretation of primary data. Examples of secondary data are research articles, books and reports. Depending on the purpose of the research, the same material can be considered both primary and secondary data. Thus, the same article as the subject of research will be the primary data, and as the material containing information about the subject of the research, the source of secondary data.

When analyzing both primary and secondary data on people with mental health problems, it is necessary to be vigilant about the protection of personal data. In this context, it is necessary  to be vigilant of biased and prejudiced approaches. When analyzing secondary data, there is a high risk of reaffirming the prejudices of those analyses. For additional information on these and other risks, see chapter 2.1 "Desk research."

## 1.5.  Research Data Processing and Analysis

Qualitative or quantitative data alone cannot show or confirm anything but must be analyzed. For each data type, the ways of processing and analysis of the data are different.

### 1.5.1. Quantitative Data Analysis

Quantitative research collects and analyzes measurable data, that is, data that is based on numbers, or data that can be easily converted to numbers without losing the meaning. Because quantitative data analysis refers to the analysis of numbers, it, therefore, involves statistics ranging from the simplest calculations to the extraction of complex analyzes.

Simple mathematical calculations or statistical analyses are used to identify commonalities or patterns of data. The results are mostly presented in graphs and tables.

Software such as Excel or SPSS can be used for data processing to reveal the average points, the number of responses given, the ratio between two or more variables, or the causal relationship to determine the reliability or validity of the results.

### 1.5.2. Qualitative Data Analysis

As for quantitative data analysis, for qualitative data analysis  (including texts, images, videos), software programs can be used to process, group, and filter information. However, the researcher must also instinctively approach the process of data analysis consciously, and be vigilant about the implications and the unexpected conclusions that will be made as a result of data analysis.

As it can be seen  from the picture, the process of any kind of analysis, and this can be related to the analysis of quantitative data, is a comprehensive, complex process, it assumes for the researcher to be as close as possible to the primary data, from preliminary collection to conclusion. It is a procedure that requires the sorting and systematization of primary "raw" data, systematic coding, appropriate reflective analysis of data, interpretation of meaning, disclosure, and relevant conclusions. And during all this time, we must be careful that the general logic of the research the idea is preserved, the research questions, the goal, the problems and the methodological limitations are not forgotten.

Picture

(Research Question Objective and Problem Methodological Limit Relative economy Maintain a deep sense of general design Collect Process data Classify Code and enter Analyze Look for meaning Comment Unfold the findings Conclude Process numbers Work with words Descriptive Statistics Logic and methods Conclusion-based statistics Reflective Analysis Process Source: O'Leary, Z. 2017. "The Essential Guide to Doing Research.")

Maintaining the general idea of research means to critically and reflexively analyze the relationship between the data and the general scope of the research. For this purpose, the researcher may periodically ask himself/herself the following questions:

- How should the data be handled to best answer the research questions?
- What is expected to be revealed and how can it be revealed?
- How do the conclusions relate to the research questions?
- Do the conclusions support the hypothesis? How?  Why? Why not?
- Does the theory help to explain the conclusions? How?
- Can the unpredictable findings be related to alternative theories?
- How can the methodological gaps affect the conclusions?
- Can the findings be interpreted differently? What will be the consequences?

As in other stages of research, in the stage of data processing and analysis, the researcher should refrain from prejudiced, biased approaches.
According to some experts, one of the most common forms of prejudice is when a researcher formulates a hypothesis or belief on a topic and uses his / her data sources to confirm that belief, opinion, or hypothesis. Experts distinguish, among others, the following situations, which may lead to prejudice-based, consequently, unreliable conclusions:

- use of biased terms and definitions,
- prejudices that confirm the researcher's assumptions,
- researcher's biased and prejudiced approaches.

The researcher must be aware of his/her possible preconceived and prejudiced approaches. It may be helpful to make a list of possible biases in advance and to check from time to time whether the researcher's actions are not driven from his/her biased approaches and opinions.

Preconceptions and prejudices can also be re-established through data processing software if the encryption instructions given to those programs contain biased approaches.
The researcher should be careful when using automated translation tools that can convey or form a biased approach, from the use of terms to the formulation of sentences or thoughts.
When processing research data on persons with disabilities, the researcher can also be influenced by approaches based on the medical or social model of disability, a patriarchal approach where the words of third parties take on more weight than the words of the person with disabilities, as well as the approach when the person with disabilities  views himself/herself as a sick person who cannot lead an independent life and be happy.

One of the techniques used to increase the research validity and to check and verify the data is using triangulation - using more than one source of data to verify the accuracy of each source; to the data with the participants; double-check the accuracy of interpretations of cases and situations whith those present in the former; and to present the complete research methodology, which will allow to replicate the research.[18]

To reduce the risks of these and other biases in data processing, one can:

- ensure the diversity of people involved in data coding and processing,
- ask research participants to review the data and the conclusions and ask them to indicate whether they express their own beliefs and explain why yes or why no,
- check and compare the data and the findings with other sources,
- try to find alternative interpretations of the data,
- ask other people, experts, and colleagues to review the findings and present their opinion about them.

## 1.6. Report Development

The research findings, the collected and verified data can be used for preparing various types of statements, reports, academic articles, and other materials (hereinafter referred to as the report) and/or to intervene and to take actions in certain situations. This information is usually used not only by the developer, institution or organization but also by others - academia, research organizations, government agencies, local and international organizations, embassies of intergovernmental organizations, etc.

Reports are usually developed for internal and external use.

● Reports for internal use are mainly developed and used by research organizations, governments, embassies, interstate, national organizations or others among the staff-members. They are not published for the general public; they aim to record the situation, assess it, and initiate appropriate actions. Based on them, the domestic and foreign policy of organizations and states, and the priorities of bilateral relations are developed.
● Reports for external use are developed by the major local and international public and research organizations, academic associations and individuals. They aim to inform the public, the government, and international actors about the state of human rights and push for action.

Report development work is usually underestimated. People may think that this is superfluous and useless, but in reality, it is a powerful way to influence the state of the human rights system. Reports ensure the decision-makers' transparency and accountability, fact-based policies.

Reports may vary depending on the situation and the developer, but there are three main types:

- Periodic reports - when the issue under study is reviewed periodically on a daily, weekly, monthly, quarterly, semi-annual, or annual basis. Periodic reports focus on the development of the state of human rights. They can be about the general situation or specific issues. When writing periodic reports, a general overview of the situation can be given. A standardized template or an example for

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[18] International Encyclopedia of Human Geography, 2009,Triangulation, https://www.sciencedirect.com/topics/social-sciences/triangulation

reports can be developed and saved for later use. This will save the researcher time and help him/her maintain the logical structure of the reports. Periodic reports are like an archive. Their systematic keeping will facilitate the researcher's further work, becoming a database.

- Special reports are written on narrower topics and a clearer range of cases. One such example is the reproductive health issues of women with mental health problems.
- Emergency or urgent reports are written when an emergency occurs, and there is a need for a quick response.

When writing reports, indicate the information source and assess its reliability. If it has been impossible to verify some of the information or the authenticity of the source has not been established, this should be noted. Words such as "alleged" or "reported" may be used when referring to human rights violations that have not yet been verified.

When the report contains confidential or anonymous information, in case of necessity, the information should be encrypted, taking into account the personal data protection and the personal security guarantees. It is necessary to ensure a balance of information, which on the one hand will ensure accountability and transparency, on the other hand, will securely provide information.

The text should be clear and concise. When presenting information, you should use the most objective formulations possible, be balanced, and describe the situation impartially. Direct quotes can be used if possible. This should be noted when adding personal comments to make it easier for the reader to distinguish between facts and comments.

It is of paramount importance to specify which rights have been violated, including state analysis and, if necessary, trend information. We should not forget to mention the positive developments, the steps taken towards and the efforts put for those developments. The report should generally contain a conclusion and recommendations. Recommendations should be action-oriented and addressed at decision-makers.

The report should be written immediately. If the report writing is delayed, the researcher may forget some details; and the details of one case may be confused with another.

*Accessibility of Reports*

The research findings and reports should be published in accessible formats. This will help for as wide a group as possible be able to get informed and acquainted with the material. This is not only about translations into foreign languages, but also about the actual formats. For example, some groups prefer to read research studies in print, for some groups the electronic version is most convenient. It should be noted that people like to search for words before reading the whole thing. It helps to understand how useful reading will be, so research studies should be presented in such a way that it is possible to search, copy passages, etc. It is desirable that the research findings are presented also in an easy-to-read version. In this version, the sentences are as short as possible, each sentence expresses one thought. They can be accompanied by pictures that will help people with mental health problems and children understand the material more easily.

The development of an audio version or the development of podcasts (audio programs) based on them also can be used. Some research studies, especially quantitative ones, can be presented with separate infographics and animated videos. The more people read the study, the more likely it is to be influential in terms of advocacy. It is desirable to present some research studies also in the form of panels. This is an accepted work style, especially during conferences and seminars.

In addition to the main research report, concise versions can also be developed, summarizing the topics. This will help policymakers who feel short of time  or are skeptical of various studies.

## 1.7. How to Use the Research Findings?

Research is often used to advocate for policy change. For this purpose, research studies are  used by researchers, other individuals and organizations when the results are published.

In some cases, the research is conducted only for advocacy and is often called advocacy research. They are implemented mainly when the advocacy groups are not able to demonstrate in any other way that this or that problem exists and should be addressed. Of course, in the case of research conducted for this purpose, the result may not be what was expected if all the rules of academic conduct are followed. This risk can be neutralized when literature review and other preparatory work are carried out before planning the research. Advocacy should be always based on the facts revealed by the research.

Here are some cases when the research findings may be useful for advocacy:

- When there is no policy, and there is a need for it. The researchers may be already working with the authorities to develop a policy; the research results are needed to organize the actions in the right direction. For example, when activists and doctors initiated research at the beginning of the HIV outbreak, to promote policies for public awareness and medical treatment, both in government and in the medical community. The same can be said about the rights of persons with mental health problems. For example, when there is no policy of deinstitutionalization, and the impact of institutionalization on people is not well studied.
- When there is a critical situation but no one notices or does not want to notice. E.g., the unavailability of medication for people with mental health problems. Studying the problem can help attest its urgency and prevalence.
- When the current policy or funding of the issue is subject to review by legislators or other policymakers. Relevant research can change the opinion of policymakers by making it fact-based. E.g., when services are centralized instead of community-based, research can be used to demonstrate the ineffectiveness of centralized services in terms of cost-effectivity.
- When the policy is under discussion: it is necessary to make sure that potential issues are not ignored. Too often, the best policy in a given situation involves taking some difficult action that policymakers or the public prefer not to take. Appropriate research can help show the need to choose the right path, even if it is painful. For instance, legal research can show the scope of legal issues, and the international obligations of the state in the abolition of compulsory treatment.
- When the policy is approved but the results are not yet visible. In this situation, evaluation research can be conducted to determine whether the current policy is appropriate or not. For example, an assessment can be made based on the concept of constitutional reform to understand the extent to which current work contributes to suffrage of people with mental health problems.
- Research can help when there is a fear that current policies are going in the wrong direction. If there is information that policymakers are going to make a serious mistake, research can save the situation before it causes harm. For instance, if there is information that a group of people is advocating for a program that will affect people with mental health problems, one can pre-study the literature, find similar situations, and influence decision-making.

Presentations and discussions are among the means of research-based advocacy. They create platforms for dialogue between researchers, activists, and concerned policymakers.

The research findings can be disseminated through both official and unofficial channels, through the postal service or in person, or can be passed through personal contacts.

## References Used in Developing this Section

*Guides and Manuals*

1. Balasanyan, S. Vardanyan, N. A Guide to the Practical Development of Research Capacities in Civil Society Organizations https://www.crrc.am/wp-content/uploads/2019/03/Research_Skills_for_CSOs.pdf
2. Tadevosyan, G. Qualitative Social Research. Theory, Methodology and Method. Educational Manual. 2006. https://www.martirosian.am/wp-content/uploads/%D5%88րակական-սոցիալական-հետազոտություններ.pdf
3. A. Bogner, B. Littig, W. Mentz Interviewing Experts. https://link.springer.com/book/10.1057%2F9780230244276
4. Family Health International, Research Methods: A Data Collector’s Field Guide, https://guides.library.duke.edu/ld.php?content_id=11691400
5. K. Thompson Experiments in Sociology, 13.01.2016, https://revisesociology.com/2016/01/13/experiments-in-sociology/
6. L. M. Vaughn, F. Participatory Research Methods – Choice Points in the Research Process, Jacquez, https://jprm.scholasticahq.com/article/13244-participatory-research-methods-choice-points-in-the-research-process
7. N. James Scientific Experiment: Definition and Examples, https://study.com/academy/lesson/scientific-experiment-definition-examples-quiz.html
8. Organization for Autism Research, Five basic types of research studies https://researchautism.org/five-basic-types-of-research-studies/
9. R. Strecker Qualitative vs. Quantitative Research, 07.11.2020, https://www.scribbr.com/methodology/qualitative-quantitative-research/
10. Sociology Group, Advantages and Disadvantages of Interview in Research https://www.sociologygroup.com/advantages-disadvantages-interview-research/
11. University of Newcastle Library, What are research methods, 15.09.2020, https://libguides.newcastle.edu.au/researchmethods. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4212209/
12. Baarnhielm, S., & Ekblad, S. (2002). Qualitative research, culture and ethics: A case discussion. Transcultural Psychiatry, https://scholar.google.com/scholar_lookup?title=Qualitative%20research%2C%20culture%20and%20ethics%3A%20A%20case%20discussion&author=S.%20Baarnhielm&author=S.%20Ekblad&journal=Transcultural%20Psychiatry&volume=39&issue=4&pages=469-483&publication_year=2002
13. Example of an Observation Card: “Accessibility of General Education Schools. Rule of Law” Study,“ Disability and Inclusive Development ”NGO, 2018 https://transparency.am/files/publications/1547306001-0-256208.pdf page 36
14. The Essential Guide to doing research. O’Leary, Z. 2004, 2010 Sage, London. https://uk.sagepub.com/en-gb/eur/the-essential-guide-to-doing-your-research-project/book249279#resources
15. Issues of validity and reliability in qualitative research Noble H, Smith J. Evidence-Based Nursing 2015;18:34-35. https://ebn.bmj.com/content/18/2/34

16. Austrian Academy of Sciences, ‘The problem-centered expert interview’. Combining qualitative interviewing approaches for investigating implicit expert knowledge https://www.tandfonline.com/doi/full/10.1080/13645579.2020.1766777
17. D. Polit, Ch. Beck Generalization in quantitative and qualitative research: myths and strategies, National Library of Medicine, 03. 07.2010, https://pubmed.ncbi.nlm.nih.gov/20598692/
18. Andre-Barron, D., Strydom, A., & Hassiotis, A. (2008). What to tell and how to tell: A qualitative study of information sharing in research for adults with intellectual disability. Journal of Medical Ethics, 34, 501–506, DOI:10.1136/jme.2006.019521
19. Balcazar, F. E., Keys, C. B., Kaplan, D. L., & Suarez-Balcazar, Y. (1998). Participatory action research and people with disabilities: Principles and challenges. Canadian Journal of Rehabilitation, 12, 105–112, https://psycnet.apa.org/record/1999-13040-004
20. Gates, Bob & Waight, Mary. (2007). Reflections on conducting focus groups with people with learning disabilities Theoretical and practical issues. Journal of Research in Nursing. 12. 111-126, https://www.researchgate.net/publication/258155970_Reflections_on_conducting_focus_groups_with_people_with_learning_disabilities_Theoretical_and_practical_issues
21. Research design: qualitative, quantitative, and mixed methods approaches / John W. Creswell, PhD, Department of Family Medicine, University of Michigan, and J. David Creswell, PhD, Department of Psychology, Carnegie Mellon University. Description: Fifth edition. | Los Angeles: SAGE, [2018] | https://edge.sagepub.com/creswellrd5e
22. The Essential Guide to Doing Your Research Project. 3RD Edition. Zina O’Leary. 2017
23. Essentials of Research Design and Methodology. Geoffrey Marczyk, David DeMatteo, David Festinger. 2005
24. Handbook of research on contemporary storytelling methods across new media and disciplines / Lorena Clara Mihaes, Raluca Andreescu, and Anda Dimitriu, editors. 2021

*Research Materials*

25. Dowse, L. (2009). “It’s like being in a zoo.” Researching with people with intellectual disability. Journal of Research in Special Education Needs, 9, 141–153, https://www.researchgate.net/publication/227847828_%27It%27s_like_being_in_a_zoo%27_Researching_with_people_with_intellectual_disability
26. Kramer, J. M., Kramer, J. C., Garcia-Iriarte, E., & Hammel, J. (2011). Following through to the end: The use of inclusive strategies to analyse and interpret data in participatory action research with individuals with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 24, 263–273, http://sites.bu.edu/yell/files/2015/09/Kramer-et-al-2011-Following-through-to-the-end.pdf

S. Mantzoukas, Issues of Representation Within Qualitative Inquiry, https://www.researchgate.net/publication/8413776_Issues_of_Representation_within_Qualitative_Inquiry

28. Decoding of Bias in Qualitative Research in Disability Cultures: A Review and Methodological Analysis. Beata Borowska-Beszta. International Journal of Psycho-Educational Sciences, Vol. 6, Issue (3), December –2017 https://files.eric.ed.gov/fulltext/EJ1254992.pdf
29. Frey, Bruce B. “The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation.” https://us.sagepub.com/en-us/nam/the-sage-encyclopedia-of-educational-research-measurement-and-evaluation/book245469

30. Caldwell, K. (2013). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. Qualitative Research, 14(4), 488–507. doi:10.1177/1468794113490718

31. Head, A., Ellis-Caird, H., Rhodes, L., & Mengoni, S. (2021). "It was really good, she sort of took some words what happened, like what I would say": Adapting dyadic interview techniques to capture the stories of marginalised voices in research. https://researchprofiles.herts.ac.uk/portal/en/publications/it-was-really-good-she-sort-of-took-some-words-what-happened-like-what-i-would-say-adapting-dyadic-interview-techniques-to-capture-the-stories-of-marginalised-voices-in-research(0a46b15b-6d7f-437d-b047-435e4d261d67).html. QMiP Bulletin Issue 31 Spring 2021. https://shop.bps.org.uk/qmip-bulletin-issue-31-spring-2021

32. Disability research and policy: current perspectives / edited by Richard J. Morris. p. cm. Includes bibliographical references and index. ISBN 0-8058-5337-5 (cloth: alk. paper). 2006
33. Polczyk, P. (2012). Autoethnography as an Accessible Method of Research. Forum Oświatowe, 2(47), 175-182. http://forumoswiatowe.pl https://core.ac.uk/download/pdf/51278858.pdf
34. Stephens Griffin, N. D., & Griffin, N. C. (2019). A Millennial Methodology? Autoethnographic Research in Do-It-Yourself (DIY) Punk and Activist Communities. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 20(3). https://doi.org/10.17169/fqs-20.3.3206. https://www.qualitative-research.net/index.php/fqs/article/view/3206
35. How is Disability Seen? An Auto-Ethnographic Exploration of Disability in Urban Townships in Ethekwini, South Africa. Connie Chao SIT Study Abroad . Fall 2019. https://digitalcollections.sit.edu/cgi/viewcontent.cgi?article=4157&context=isp_collection
36. Disability, advocacy and coping: an autoethnography on non- visible disability. Dana L. Morella. San Jose State University. https://scholarworks.sjsu.edu/cgi/viewcontent.cgi?article=4481&context=etd_theses
37. Mills, Albert & Durepos, Gabrielle & Wiebe, Elden. (2010). 15. Mills, A. J., Durepos, G., and Wiebe, E. [Eds.] (2010) Encyclopedia of Case Study Research, Volumes I and II. Thousand Oaks, CA: Sage. https://bayanbox.ir/view/2229366504315040052/ENCYCLOPEDIA-OF-CASE-STUDY-RESEARCH-2.pdf

# 2. AN OVERVIEW OF THE IMPLEMENTATION OF PARTICULAR TYPES OF RESEARCH PROJECTS

*This section presents specific types of research, in particular, the literature review, the study of open data of legal analysis, basic information on human rights monitoring, and the specifics of such research studies in the field of mental health.*

## 2.1. Desk Research: The Study of Secondary Data and Literature Review

During the desk research, studies of secondary data and literature review are carried out. The secondary data are the existing databases, reports, and documents, which, as a rule, have been compiled by other organizations and people, and for other research purposes. The literature review is often the main source of information about the political, economic, and social situation. In contrast to the study of secondary data, the literature review presupposes the study and implementation of analyses, conclusions, and final reports.

The literature review is the study of a given topic and context in academic literature as well. In conducting a literature review, the researcher's goal is to find out what knowledge and ideas there have been expressed about the topic before, and what their strengths and weaknesses are. In literature review, as in all other cases, it is important to define the research goal, tasks and questions. Literature review is used both to get acquainted with the topic of research in advance, and as a separate method or in combination with other methods.

Before choosing a research topic, literature review enables one to learn about the current research studies in a given field, and to understand the range of possible research questions. Literature review is usually one of the first tasks to be undertaken after the research topic has been decided upon. Reading critical literature can help improve the topic and understand the scope of research questions. The literature review can help to find out what research has been done so far, and identify what is yet unknown within the topic.

Literature review is considered to be successful when:

- the published research and theories are summarized and analyzed,
- controversial issues are discussed,
- any omissions in previous research studies are identified.

The research-related literature can be found by asking experts in the field or by simply searching in the Google Scholar system. When conducting a literature review, the researcher should look for the literature sources using a variety of tricks and tools. For example, if a researcher studies articles about people with mental health problems in pedagogical collections, he/she should look not only for the term "a person with mental health problems" in the chosen books, but also for phrases that can help find all the possible material. The list of these words should be defined in advance, and the researcher should not be constrained to choose words that are considered offensive or incorrect. This will help to get the complete picture.

When the researcher conducts a study of non-digital materials, it implies a complete study and a separation of the related materials. In such case, too, the research objectives, i.e. its goal, must be very clear, because there is a high probability of deviation.

The researcher should save and cite all the sources, and document all the materials used in a pre-approved manner. One should know in advance what data about the used literature will be needed in the future. For example, when studying conference protocols or transcripts, their numbers, dates, pages, in case of need, their paragraphs, etc. should be written down.

During desk research, the choice of logical structure is also important. One should be more careful about the structure when the research is about issues that are less studied, or there is caution about the topic within an academic framework. A reasonable structure will help everyone easily understand the research material. For instance, a chronological or thematic structure may contribute to the accessibility of the material.

Not to diverge from the purpose of the desk research, the researcher should regularly address the following questions:

- What are the specific hypothesis, research objective and research question that help to define the literature review?
- What kind of literature does the researcher want to study? Does he/she study the theory, the methodology or the policies? Does the researcher conduct quantitative research (e.g., the economic implications of institutionalization of persons with mental health problems), or qualitative research (e.g., research on the emotion of loneliness of persons with mental health problems)?
- What is the scope of literature to be studied? What kind of publications are going to be used (e.g., collections and books)? Materials in which fields the researcher is going to study (e.g., care provision, psychology, sociology, law, economics, etc.)?
- How effective was the information search? Was the search comprehensive enough to ensure that all the relevant material could be found? How was the filtering of irrelevant materials carried out? Is the number of the used sources appropriate to the used literature and the scope of the study?
- Did the researcher critically analyze the literature used? Does the researcher pay attention to the key concepts and issues in the literature studied by making comparisons? This will also help to understand whether all the authors meant the same concepts using the same terms.
- Did the researcher quote and discuss studies contrary to his/her point of view?
- Will the reader find the literature review useful and reliable?

To ensure the usefulness of the desk research, the researcher should ask himself/herself the following questions while studying each material.

- Did the author of the material formulate an issue or a question? Are they clearly defined?
- Could the issue have been approached more effectively from another angle?
- What is the author's research direction (e.g., commentary, critique, or combination)?
- What is the author's theoretical framework (e.g., biological, humanistic, behavioral, feminist, etc.)?
- What is the relationship between the theoretical and research perspectives?
- Did the author include literature that he/she did not agree with?
- How well is the research design developed (e.g., the population, the outcome, etc.)? How accurate and valid are the measurements? Is the data analysis precise and relevant to the research question? Are the conclusions based on the data and analyses?
- How does the author construct the argument? Can the researcher "deconstruct" the argument to see if it logically "breaks down" (e.g., in establishing causal links)?
- How does this or that material contribute to the researcher's understanding of the problem under study? What are the strengths and weaknesses?

## 2.2. Legal Research

Legal research is the process carried out by lawyers and researchers to study the legal framework of an issue or a topic. It is also practiced by lawyers when deciding what laws to apply to the facts of their case, how the facts are relevant to their claims, what arguments may be required in extrajudicial or judicial proceedings, and what other precedent decisions may matter.

Legal research must be comprehensive and accurate. When a researcher intentionally or accidentally omits one of the sources that completely or partially contradicts his/her claims, the other sources of the research become invalid and incomplete. For this purpose, when conducting legal research, it is important to define a strategy and adhere to it, which will save the researcher’s time, and ensure integrity.

When conducting legal research in the field of mental health, it is important that the researcher does not become entangled in legal controversy. Various legal acts and research studies may be out of date - outside the developmental trends of law.

The researcher must first make sure that he/she understands the issue under study. Issues of persons with mental health problems are various, they have a lot of direct and indirect causes, and they can be difficult to understand if not considered separately.

As a solution, one should read the most recent academic and non-academic publications on the issue under study, such as media articles, essays, etc. written by or with the involvement of persons with mental health problems. The researcher must make sure that he/she understands the problems as much as possible and has all the necessary facts. To be successful in research, one needs to understand the issues and be able to stay focused on them.

It is easy to deviate from directly related topics and go only to easily found materials. By first identifying the research purpose and regularly focusing on the problem, the researcher can avoid that trap. If the researcher started with the main sources (such as laws) but got lost and was not able to find documents with the selected search terms, then he/she should probably go back and start researching secondary sources to find relevant materials and search terms. The study of secondary sources is important when the researcher knows nothing about mental health policy or legislation. Secondary sources often explain the legal principles in more detail than the laws, so they help save time.

When defining the scope of research, it is important to consider the question of geography. Legal rules may vary depending on where, in terms of geography, the researcher is looking for the answer to his/her legal question. The right to mental health has not developed in the same direction in all places and, depending on the region, the legal practice and regulations may be different.

One of the difficulties in this field is overcoming the stereotype of seeing the solution to all problems in the person's medical treatment and recovery. The study of the human rights model of disability will help to understand that, regardless of the person's health status and abilities, it is possible to secure their rights when the perspective shifts to environmental barriers.

Consulting with a mental health rights expert can help as well. If the project does not prohibit consultation, one can ask for help from someone who can advise on research strategies or who can offer search terms.

The research study should not be considered a failure if the answer is not found. If the researcher found material that could be used to formulate the argument, the research efforts were successful. Legal research skills should then be used to develop the commonalities between the found law and the problem explored.

As the right to mental health is a developing field, the researcher is likely not to find answers to all the questions. We must remember that no answer is an answer. For example, the courts and the legislature may never have addressed a specific issue.

When conducting research in the field of the rights of persons with psychosocial disabilities and/or mental health problems, attention should be paid to what legal standards and documents the researcher accepts as a basis. The field is still in the stage of active development; it fights against the existing deep stereotypes in the system reflected in the legal field as well. Many of the legal standards used in the past are being reviewed. The implementation of human rights standards for persons with psychosocial disabilities and/or mental health problems are being redefined to eliminate stereotypical and discriminatory approaches that have unnecessarily restricted the rights of persons with psychosocial disabilities and/or mental health problems. Currently, the most up-to-date and law-based standards in the field are defined by the Convention on the Rights of Persons with Disabilities and the general comments of the UN Committee on the Rights of Persons with Disabilities. The approaches promoted by the World Health Organization's Quality Rights initiative are also progressive.

## 2.3. Open-source Research

Currently, a lot of data are available on the Internet, and the rapidly evolving digital space has led to the emergence of new types of information and sources. These data can help identify alleged human rights violations and serious offenses.

Open-source research studies are studies that rely in whole or in part on publicly available information for conducting systematic online research of alleged violations of law.

are used for open-source research. Sometimes, the term "Online Open-source Investigations" (OOSI) is used, in some cases, "Open Source Investigations" (OSI), and in other cases, "Open-source Intelligence" (OSINT). All these terms are used by specialists and in the literature but there are some differences between them. So, the difference between OOSI and OSI is that OOSI refers to investigations that use only online sources, OSI uses not only online sources.

Some people prefer to use OOSI or OSI instead of OSINT because they think the term OSINT is more relevant to specific intelligence services. For these agencies, OSINT is part of the intelligence resource system which includes HUMINT (human intelligence), SOCMINT (social media intelligence), IMINT (image intelligence), and more. However, this term is still widely used and is probably the most common.

Open-source information is the information that any member of the public can view, obtain, or request without special legal status or an authorized access. Digital open-source information is the publicly available digital information typically obtained from the Internet.

Open-source information can include data such as the content, documents, pictures, videos, recordings, satellite photos, government-published data, etc. posted on social media.

Thus, the following open data sources can be distinguished that can be used by the researcher to obtain information:

1. Geographical or geo-data - help to locate the place of a building or an event, boundaries, etc. This information, for example, can help to determine the location of human rights violations through photos or videos, understand the places of detention, etc.
2. Cultural data --Cultural works, historical and cultural monuments, and other related data are processed and published mainly by libraries, galleries, archives, and museums. These data can be valuable in terms of research when the latter, for example, relates to the works by persons with psychosocial disabilities and/or mental health problems or their depiction or the reflection of their life-stories' in works.
3. Scientific data - These data are processed within the framework of scientific research. These data can be useful in the research design stage and in the literature review - when it is necessary to substantiate or understand the phenomena that have been recorded but are beyond the scope of the research problems.
4. Financial data - These data summarize the government's financial expenditures and the financial market in general. They can be used when researching the cost-effectiveness of the mental health system and when making policy proposals related to the budget. Or, for example, when studying the additional costs by people with mental health problems compared to the costs by people without mental health problems.
5. Statistical data - These data are processed by statistical centers and include census or data collected by socio-economic indicators. These data include the number of persons with mental health problems, their place of residence, age groups, the nature of their health problems, etc.
6. Climate data - These open data can be obtained from satellites or other sources that inform about the weather or climate change. These are important for researchers, especially when examining the effects of precipitation on human health and behavior, or the effects of climate change on specific groups of people.
7. Environmental data - this Information includes geographical features (e.g., mountainous, large rivers, man-made reservoirs, etc.), pollution, etc. This data can be useful in a variety of studies, including those conducted by the participatory observation method attempting to find relationships between human behavior and the habitat.
8. Data published by state bodies - Governments often publish open data to ensure the transparency and accountability of their activities. These data include, for example, the data on the ongoing work in the mental health action plan, the evaluation results, etc..

Open sources have become useful tools for researchers in both the research initiation and implementation stages. In recent years, attempts are being made to coordinate and regulate their use.

In December 2020, the UN Human Rights office and the Human Rights Center of the University of Berkeley together developed the Berkeley Protocol on Digital Open Source Investigations which is the first practical guide to using public digital information, including photos, videos and other types of information posted on social networking sites, such as the Facebook, Twitter, and YouTube for international inquiries of human rights violations and criminal investigations.

It describes the professional standards that must be applied to the disclosure, collection, storage, analysis, presentation, and use of open-source digital information.

The protocol states that organizations should seek the services of experienced cybersecurity professionals in a case of high risk, such as in cases of studies involving particularly vulnerable victims.

A separate section of the protocol is dedicated to the vulnerability; this section describes the vulnerability of individuals in viewing graphic content including cruelty, and other work-related difficulties, that may be more dangerous for mental health research team members with sensitive emotional state.

The Bellingcat platform, where researchers make extensive use of open source intelligence tools, also urges to pay attention on the likelihood of traumatic experiences in researchers' work and on the need to take action to that end.

In the case of open-source research, it is also important to remember the vulnerability of personal data. There are many materials on the Internet that  publicize information about a person in a psychiatric institution - medical diagnosis, photos, etc. For instance, in the Armenian Datalex database of the judicial system, in judicial cases with the involvement of persons with psychosocial disabilities and/or  mental health problems, it is often possible to find a person's medical diagnosis and information about the state of their mental health. The researcher should not reproduce such sensitive personal data without the direct consent of the person. Most often, in this case, means of impersonalization and covering the face and other personalizing data (for example, tattoos and clothes)  in photos are used.

As with other types of research, the researcher's bias and prejudice's  may affect the quality of research based on open- source data. It can impact all the stages of source selection, information filtering and analysis. In this case, the researcher should consciously approach his/her biased and prejudicial approaches and take measures, including triangulation, representation, and participatory tools, to ensure that his/her biased approaches to psychosocial disability and/or mental health problems do not affect or affect the research results as little as possible.

## 2.4. Human Rights Monitoring

Human rights monitoring is the term used to describe the collection, verification, and use of information to address human rights issues. It usually requires a long period of time.

The purpose of human rights monitoring is to improve the state of human rights. It can be carried out through a combination of different actions, such as recording the events that have taken place (or are taking place) and influencing the local authorities, forcing the government to respond or fix the situation, raising public awareness on human rights abuses, etc. The appropreate form of monitoring depends on the current situation in the country or region.

When conducting human rights monitoring, it is important to identify the human rights standard  underlying the monitoring process. To find out whether the State respects the human rights  of persons with mental health problems, two main levels must be considered. The first is the international legal regulations on human rights, and the second level is the domestic legislation.

For monitoring, researchers are not required to have detailed knowledge of international regulations on human rights, rather they should be familiar with the basic principles and issues, and be able to understand what can be considered a human rights violation and what cannot be considered as such.

Information about human rights violations, like any other information, is subject to verification from other sources. Exceptions may happen when it comes to a person's life and health issues. The main tools for checking the validity of information are interviews, documents, documentation of physical injuries, other materials, site visits, etc.

There are three important principles in this process:

- Check the reliability of the source - Is he/she a victim of violence, a person present, or has he/she heard other people talk? Does the information come from the first, second, or third hand? What is the motivation of the source to talk about the issue? One must be attentive in answering these questions. For example, victims may experience emotional distress when talking about the incident, or when a question is formulated in a way that the source concludes that the researcher doubts the veracity of the information. Questions should be asked directly but sensitively.
- Correspondence of information gathered from independent sources - Are there other independent sources of information that would confirm the information on the alleged human rights violations? Are these sources not interrelated? If unrelated sources give matching information, it is more likely that the information provided by the first source is true but verifying it from another source will increase the validity.
- Contextualized monitoring - The information provided by the source should be consolidated with the human rights situation in the country, town, or village. What is its likelihood? Have similar cases been registered before?

**References Used in Developing this Section**

*Guides and Manuals*

37. Skåre, S., Burkey, I. and Mørk, H., 2008. Manual on human rights monitoring. Oslo: University of Oslo, Norwegian Centre for Human Rights. https://www.jus.uio.no/smr/english/about/programmes/nordem/publications/manual/current/kap6.pdf
38. OHCHR, 2001. Training manual on human rights monitoring. Geneva: UN. https://www.ohchr.org/documents/publications/training7introen.pdf

39. Andreassen, B., Sano, H. and McInerney-Lankford, S., n.d. Research methods in human rights. https://books.google.am/books?id=7lPYDgAAQBAJ
40. Internews, 2021. Speak Up, SpeakOut: A Toolkit for Reporting on Human Rights Issues. 2020. https://issuu.com/saladeprensa/docs/speak_up_speakout-_a_toolkit_for_reporting_on_hum
41. The Language of Legal Correspondence, Yerevan, YSU edit., 2019, 202 page ISBN 978-5-8084-2370-1 http://publishing.ysu.am/files/Iravakan_gragrutyun.pdf
42. Berkeley Protocol on Digital Open Source Investigations. https://www.ohchr.org/Documents/Publications/OHCHR_BerkeleyProtocol.pdf https://www.ohchr.org/EN/NewsEvents/Pages/berkeley-protocol.aspx
43. First Steps to Getting Started in Open Source Research. https://www.bellingcat.com/resources/2021/11/09/first-steps-to-getting-started-in-open-source-research/
44. Guide to Open Source Research for Human Rights. https://osr4rights.org/
45. Digital Witness. Using Open Source Information for Human Rights Investigation, Documentation, and Accountability. https://global.oup.com/academic/product/digital-witness-9780198836070?cc=gb&lang=en&
46. DATNAV: New Guide to Navigate and Integrate Digital Data in Human Rights Research. https://www.theengineroom.org/datnav-digital-data-in-human-rights-research/
47. A Guide to Open Source Intelligence (OSINT). https://www.cjr.org/tow_center_reports/guide-to-osint-and-hostile-communities.php
48. Open Research Software and Open Source. https://opensciencemooc.eu/modules/open-research-software-and-open-source/
49. Cognitive Bias and Critical Thinking in Open Source Intelligence OSINT . https://vimeo.com/114220686
50. Open Source Investigations for Human Rights. https://freedomlab.io/open-source-investigation-for-human-rights/

# 3. LEGAL AND ETHICAL ISSUES IN RESEARCH

*This section presents the international and national legal provisions regulating the relationships during research, including research with the participation of vulnerable groups, as well as the ethical principles and the principles of ensuring the rights of the individual.*

## 3.1. Legal Issues in Research

Article 31 of the UN Convention on the Rights of Persons with Disabilities obliges states, in implementing the Convention, to compile statistical and research data for policy development.

While compiling statistics and conducting research, for the process of obtaining and maintaining information, the Convention sets out the following criteria:

- confidentiality of personal data, respect for personal data, compliance with legal norms on data protection, including national legislation,
- protection of human rights, fundamental freedoms, and ethical principles defined by international norms.

The European Convention of Human Rights and Biomedicine or the Oviedo Convention sets out provisions for the protection of the rights of persons participating in biomedical research. Armenia has not yet signed and ratified the Oviedo Convention, so it is not mandatory for Armenia. This Guide does not specifically address research in the field of biomedicine, however, the provisions of this Convention can be applied as exemplary standards in all cases where research may have an impact not only on the physical but also on the mental health of the individual.

Article 16 of the Oviedo Convention sets out the conditions to be satisfied simultaneously under which only can research with human involvement be carried out. These conditions are:

- Research on humans has no alternative with comparable effectiveness;
- The potential risks to the person are commensurate with the potential benefits of the research;
- The competent authority approves the research project after a multidisciplinary independent examination of its scientific value, including the research purpose and the ethical acceptability.
- The human participants were informed about the guarantees provided by law for the protection of their rights;
- Explicit and properly documented informed consent was given. The consent can be withdrawn at any time without hindrance.

Ensuring human dignity and equality is a cornerstone in research within the framework of human rights and fundamental freedoms defined by international and domestic legal norms. In the case of people with psychosocial disabilities and/or mental health problems, it is a challenge, given the stereotypical "patriarchal approaches" prevailing in the field and the need to make sufficient efforts to make research inclusive.

The Constitution of Armenia recognizes the dignity of the person as an inviolable value, as well as the person’s right not to be discriminated against, and the right to physical and mental immunity.

The Constitution, the RA Law on the Rights of Persons with Disabilities, recognizes the respect for the private, personal life of the individual. The RA Law on Personal Data Protection stipulates guarantees for personal data protection during personal data processing. According to the RA Law "On Personal Data Protection", personal data processing is any action, regardless of its form or manner, related to the collection either fixing or entering or coordinating or organizing or storing or using or transforming or restoring or transferring or correcting or blocking or destroying, or performing other actions. That is, the guarantees of the

RA Law on Personal Data Protection apply to the implementation of all actions related to personal data within the framework of the research.

Guarantees for the protection of medical confidentiality are also defined by the RA Laws “On Medical Care and Service to the Population " and "On Mental Health Care."

The right of a person to act freely is defined by the Constitution of the Republic of Armenia, and the Law of the Republic of Armenia on the Rights of Persons with Disabilities defines the possibility for a person with a disability, including a person with psychosocial disability and/or mental health problems, to make decisions about his/her daily life on equal basis with others, and the right to realization of his/her fundamental rights, amongst them, the right to reasonable accomidations, including various types of support. Armenian law still allows a person to be declared *incapacitated*, in which case the right to making decisions is transferred to the person's guardian. According to the Decision-1197 of the Constitutional Court of RA, April 7, 2015, the European Court of Human Rights, in its decision "Nikolyan v. Armenia", criticized the mechanism of recognizing a person *incapacitated*, and called for introduction of a decision-making support system. When conducting research, regardless of whether the person is declared *incapacitated* or not, the researcher should be guided by the presumption of the person’s *capacity* and apply a decision-making support system.

The Constitution also explicitly prohibits from subjecting a person to scientific, medical, or other experiments without the person’s free, explicit consent. According to the Constitution, the person must be informed in advance about the possible consequences of such experiments. Although this provision may be considered generally concerning the clinical trials, it is important to remember that any research involving a person with psychosocial disability and/or mental health problems can have a detrimental effect on a person's mental health.

### 3.1.1. Ensuring the Right to Free and Informed Consent

Ensuring the informed consent of a person is combined with some other rights of the person to self-sufficiency, free choice, independence, non-discrimination, full recognition of equality, full capacity, and non-violence. These rights are defined in the Convention on the Rights of Persons with Disabilities, and in the field of biomedical research, the Oviedo Convention directly stipulates the right to informed consent.

Ensuring the right to truly informed consent, for example when conducting an interview or taking a photo, requires effort particularly in research involving persons with a variety of mental health states or mental health problems. It is also difficult to assess whether the consent was indeed voluntary and informed, and the provision of this condition mostly depends on the researcher’s integrity.

Often people, being or feeling dependent on the outside world, the interviewer, and the institution, may feel obliged to give their consent.

The socio-cultural characteristics of society and the person’s place of residence often do not allow the person to realize the meaning and significance of informed consent. People are also simply not ready to realize that researchers are specifically interested in their own opinion.

The researcher must realize and take into account all these possible pressures and influences that may impact a person's decision.

At the same time, it is not permissible to involve a person in any research without consent, regardless of age, gender, mental health or other conditions.

Obtaining informed consent is, at the same time, interconnected with communication and information accessability. The provision reasonable accommodations, including the language and communication with the person in an accessible manner is the basis for obtaining truly informed consent.

When requesting informed consent, the researcher should take into account, on the one hand, the person's right to and decision-making capabilities, on the other hand, the most effective means of communicating, that is, providing information about the research and listening to the person's opinion.

Informed consent may be formulated both in writing or verbal form.

In any case, the person can withdraw his/her consent and refuse to participate in the research at any time. It is necessary to inform the person about this right.

The purpose of obtaining informed consent is to give the individual a clear idea of what the research is about, how it may affect him/her, and how he/she can support the research., It is necessary to obtain the informed consent of the person for all the stages and actions of the research project. Obtaining a consent is a bilateral process. On the one hand, the person whose consent is required must be provided with clear and complete information about the research and the risks. On the other hand, that person's understanding of the relevant information must be unambiguous.

- Information should be conveyed to the person in a manner understandable for the person and appropriate to his/her age. For example, if a group of minors has been recruited for the study, the informative forms should be prepared for both 10 and 16-year-olds. For persons with some types of mental health problems and for children at the age of early childhood, preschool and school-age, and early adolescence, illustrated material may be offered that demonstrates in plain, visual language what the research participation is all about.

- It is necessary to make sure that the information is understood correctly after it's presented.

- The involvement of the person in the research should be an extreme measure in the case of persons who cannot give their consent. The use of presumed and indirect agreements is usually not acceptable. A person can not be involved if he/she expresses disagreement in any way.

Based on various guidelines, the following information can be considered necessary to be provided to a person for obtaining informed consent:

- The person’s participation is voluntary; he/she can refuse to participate at any time. Refusal will not lead to negative consequences; the person does not need to substantiate his/her refusal decision.

- Who conducts the research?

- Who finances the research?

- What are the possible conflicts of interest?

- The purpose of the research;

- Why was the person selected by the research team?

- The risks and benefits of research participation for the individual.

- The procedures and the required time for participation in the research;

- Is the person reimbursed for participating in the study (e.g., for time, for transportation or other expenses)?

- How do researchers react to accidental or unexpected discoveries?

- The researchers’ contact details;

-The terms of personal data processing: How are they processed and who has access to them? How and for how long are the data stored? Are the data transferred to other researchers, organizations, government agencies, other countries, etc.?

- The person may at any time refuse to participate in the research and prohibit the use of previously provided data. It will not lead to any negative consequences for them.

Obtaining informed consent should not be considered a one-time process. It is necessary to receive it both at the beginning of the research and during each acgtivity. For example, when interviewing, taking photos, recording, carrying out observations, etc.

## Persons Who, Due to Age or Health Conditions, are Unable to Give Informed Consent

It is important to remember that regardless of the disability or level of needs, the researcher should be guided by the presumption that the person has a decision-making capacity. Therefore, the researcher must first make sufficient efforts to provide information, check whether the person has understood it, and obtain the consent. The successful implementation of this process depends on both the researcher's ability to resist stereotypes and the material resources, as, for example, the lack of assistive technologies can complicate or make the process impossible.

In case when it is not possible to obtain the consent of the person using the possible means of informed consent, it is necessary to discuss the possibility of the person participating in that study. For example, the publication of a person's photograph which is considered biometric personal data and has special protection is not allowed without the consent of the person, except in cases where it is for the protection of the person.

Article 17 of the Oviedo Convention provides for special protection to persons who are unable to consent. According to the Convention, research on a person who is unable to give informed consent is permissible only if there is no alternative, including a person who can give consent. And in cases when the person is nevertheless involved in the research, in case of his/her objection, the research should be stopped.

The rule prohibiting from conducting research against a person's will during research is conditioned by the priority of respect for a person's autonomy and dignity in all circumstances, even if the person cannot consent. This provision is intended to ensure that either the research burden is acceptable to the individual or that he/she does not assume the research burden without his/her consent.

### Children

According to the legislation of Armenia, a person under the age 18 is considered a child. According to the RA Law on Personal Data Protection, in case of processing data of children under 16 years of age, it is necessary to obtain informed consent from the legal representative of the child - his/her parent or guardian. Children over the age of 16 consent personally. However, this does not mean that the consent of a child under 16 years of age should not be sought when processing his/her data.

The child has the right to express his/her opinion about the participation in the research, the researcher is obliged to provide the child with information about the research according to his/her age and communication needs, listen to and take into account his/her opinion. Research without the consent of the child is not allowed.

In the case of children from infancy to late adolescence, it is necessary to assess their best interests and, if possible, attitudes, taking into account their age and maturity.

When conducting research with children, one should keep in mind that the group of children is not homogeneous, it includes children of various ages - from infants to children who will soon be given the full right to make decisions about themselves by law, and who have very different physical, cognitive and emotional abilities.

### 3.1.2. Personal Data Protection

Research with human involvement usually is about obtaining information about a person. Once collected, this information is stored, processed, and often made public in one way or another. The research can make discoveries about people and publicize information that would not otherwise be published.

The researcher may have access to sensitive information, such as a criminal record.

Almost all fundamental human rights documents, including the Convention on the Rights of Persons with Disabilities, the Council of Europe Convention for the Protection of Human Rights and Fundamental Freedoms, and the Oviedo Convention, stipulate the respect for privacy.

The UN Convention on the Rights of Persons with Disabilities specifies this right by defining that the personal life, family, house, correspondence or other means of communication of persons with disabilities, regardless of their place of residence or lifestyle, must not be subjected to random or unlawful interference, or illegal steps must not be taken against their dignity and reputation.

The RA Law on Personal Data Protection classifies the data on person’s state of health and a number of other data into a special category of personal data, the processing of which is prohibited without the person’s consent, except when the data processing is directly provided by Law. The data in this category and the Biometric data of the child can only be processed when there is a legitimate reason to process such data, and processing the data of this category necessary to protect the best interests of the child.

The protection of personal data is closely interrelated to freedom of decision-making, autonomy, and preservation of authority.

The fact of living in an institution with many other people, the age, state of health or other conditions of the research subject do not in any way mean that the person does not know of or value the personal data and the right to privacy. The researcher must in each case apply maximum standards for personal data protection, without discrimination.

An important component of data protection is the person's consent. Disclosure of data, especially sensitive data that would not otherwise be available to the general public, is permissible only with direct consent.

Another important component is the data storage and destruction. The research team bears responsibility for data storage, archiving, and leakage.

An effective way to protect the data is impersonalizing it, keeping anonymity or using pseudonyms. At the same time, it is necessary to take into account that the person can be identified not only by the name but also by other data, so even in the case of anonymity or use of pseudonyms, it will be necessary to assess the risk of publishing any other information that will allow identifying the person.

From a data protection point of view, research methods that involve group work, such as the focus group discussion, can be problematic. It is impossible to guarantee the privacy of individuals in the case of group work, at least each member of the group will have access to the data. The person should be informed of the risks of personal data protection when involving in group work, and that the researcher cannot guarantee the protection of data that has been disclosed in group work.

Thus, in the field of research on the rights of persons with disabilities, respect for the dignity includes respect for the dignity of persons with disabilities, anonymity, ensuring the personal data protection, and confidentiality during the research, including when disseminating the research findings, as well as afterwards, in data storage, archiving and destruction phase. Their differences and accessibility needs should be respected during the research, for example, through the choice of accessible locations or possible alternative means of communication.

## 3.2. Ethical Issues in Research

### 3.2.1. The Ethical Issues in Conducting Research

According to the European Charter for Researchers, researchers should focus their research on expanding the boundaries of human well-being and scientific knowledge, availing themselves of the freedom to express their own thoughts and opinions, as well as the freedom to determine the methods by which issues are to be resolve, in accordance with recognized moral principles and practices.

Research ethics can be viewed as a set of moral values, virtues, principles, standards, or priorities that should serve as a guide to "good" research practices. Making "ethical" decisions during research aims to balance the potential benefits of the research, and the harm and risks that may arise for the research subjects, the participants, and the general public.[19]

The existing ethical principles for conducting research with human participation were developed based on the Nuremberg Code in 1947 and the Declaration of Helsinki in 1964. Although these principles were originally developed to regulate research in medicine, their further application in other types of research aims to protect individuals from exploitation and ensure respect for them, their autonomy, right to freely express their will, justice, and equal treatment.

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[19] Handbook of Research Ethics and Scientific Integrity: Editors Ron Iphofen: Springer Nature Switzerland AG 2020 DOI https://doi.org/10.1007/978-3-030-16759-2

It is the responsibility of researchers and other persons involved in the research process to ensure that the research project considers the specific ethical challenges and a range of possible strategies developed to meet them. This means that all research team members, including data collectors, data entry clerks, maintainers, as well as research program coordinators and funders, should receive special training.

The guarantee of conducting "ethical" research is the researchers personal commitment and the culture of the research community. However, it also becomes clear that in the case of certain types of research, it is necessary to develop regulations for researchers and research organizations.

These regulations can be formulated during the research design as the ethical principles of research. At all stages, project design, implementation, and presentation of findings, efforts must be made to ensure addressing the ethical considerations.

*The Classification of Ethical Principles*

In different years and in diverse scientific fields, the research ethics principles have been systematized and classified differently.

Thus, in the OECD (Organisation for Economic Co-operation and Development )Policy Document NO. 34 on “Research Ethics and New Forms of Data for Social and Economic Research”, the general ethical principles relating to social research are devided into two broad groups. The first group summarizes how researchers conform to each other and their own methodological criteria. Constructive criticism and publicity are key here. The second group defines how researchers treat the world and, first and foremost, the data subjects. The key principles here are respect, ensurence of good consequences (not harming), and justice.

The four American principles of biomedical ethics include: autonomy; non-maleficence; beneficence and justice. The for ethical principles in European bioethics and biolaw include vulnerability, along with autonomy, dignity and integrity. Some authors also mention the tension between the principles of beneficence (charity) and autonomy, as the principle of beneficence can be a cause for patriarchal approaches.[20]

Moreover, in the case of persons with psychosocial disabilities and/or mental health problems, one should consistently beware this danger.

According to Jacob Dahl Rendtorff and Peter Kemp, the principle of "vulnerability" ontologically precedes other [European] principles, as it expresses better than all other ethical principles […] the finitude of the human condition."

The European Commission’s document on "Ethics in Social Science and Humanities" sets out the following ethical principles:

- respecting human dignity and integrity,
- ensuring honesty and transparency towards research subjects,
- respecting individual autonomy and obtaining free and informed consent (as well as assent whenever relevant),
- protecting vulnerable individuals,
- ensuring privacy and confidentiality,

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[20] Cohen, S. (2018). The logic of the interaction between beneficence and respect for autonomy. Medicine, Health Care and Philosophy, 22(2), 297–304. doi:10.1007/s11019-018-9876-4

- promoting justice and inclusiveness,
- minimising harm and maximising benefit,
- sharing the benefits with disadvantaged populations, especially if the research is being carried out in developing countries,
- respecting and protecting the environment and future generations.

*The Principle of Reducing Harm or Risk*

The kee ethical principle is reducing harm or danger. The issue of harm can arise in different situations and have different manifestations, impact and significance. It may be controversial to define what the damage is, who is responsible for the damage, or whether in some cases damage to a certain degree can be "justified." The issue of harm can arise for the members of the research team, the research subjects, the participants, and the general public. Often it may face the problem of setting too high standards for the involvement of individuals in research, which is discussed in section 3.2.2., "The Ethical Issues and Risks of Conducting Research with the Participation of Vulnerable Groups."

In all cases, it is necessary to assess the likelihood of possible harm in a given research project, as well as the means for overcoming or reducing it, and the principles that should be the basis for making urgent decisions on the spot and defining the scope of responsibilities.

In assessing the harm or danger, the research team should refrain from stereotypical approaches, and the harm/risk management policy should not be a reaffirmation of systemic prejudices.

The protection of the rights and immunity of persons involved in the research should be a priority. The research team should make every effort to protect individuals from potential harm or danger. Such situations may include:

- Be flexible in obtaining informed consent. In some cases, written consent may put the person at unnecessary risk in the future, as it will establish a connection with the research and reveal their conditions, for example, a certain illness, use of a service, etc.
- In Security issues, be vigilant when making concessions on the basis of safety, speed, resource-saving, stereotypes and other reasons.
- Stereotypes and prejudices play a significant role – from the formulation of the initiative of conducting research on the rights of persons with psychosocial disabilities and/or mental health problems , to the publication of research findings. A research project based on stereotypes will lead to further reaffirming those stereotypes which is dangerous for individuals and society, and may harm the development of the field. To avoid such situations, it is necessary to strictly follow the provisions of the UN Convention on the Rights of Persons with Disabilities, and the Comments of the Committee, even if they contradict the established dispositions, conveniences, financial or other expediency.
- When conducting research involving human subjects, it is important to remember that even the content of the question, its wording, the body movements and gestures can be harmful, especially when they are reminiscent of past trauma. These questions are more sensitive in cases when the person is still in a dangerous, risky, traumatic situation or is vulnerable. The researcher may not always notice the harm. Therefore, for such situations it is necessary to develop possible approaches, study and develop active listening skills, in advance have a list of possible, reliable services to be advised, end the conversation by talking about the person's positive experience and future plans. An interview or another direct research action with a person who is still traumatized sometimes may not be justified.

●Within the framework of the research, a data set about the person is collected, for the storage of which are responsible the data collector, the data keeper and the whole research team. This information includes contacts, health state, location, services used and other data. It is necessary to have a clear policy on who will have access to the data, how that data should be stored, and when it should be destroyed.

● During research, research team members may witness or be informed of offenses, including alleged criminal offenses. This situation involves both ethical and legal considerations. The researcher, as such, is not protected from the legal consequences of not informing the law enforcement agencies about the information that became known to him/her. In some cases, Armenian law obliges a person to provide information about a criminal act that the person has witnessed or learned about. The RA Criminal Code establishes liability for refusing to testify as a witness or victim, as well as for failing to report only a well-known serious or particularly serious crime being prepared. On the other hand, the researcher may be limited by the will of the respondent, the participant of the research, who demanded to keep his/her data, the information received about him/her confidential. However, these obligations should not prevent the documentation of violations, speaking out about them, and excessive caution should not impair the research quality. In all cases, it is necessary to anticipate these dangers, to take into account that at any stage the researcher may be obliged to provide information to law enforcement agencies, the participant should be warned about it, and mechanisms for the protection of the participant should be provided.

*The Well-being of Research Team Members*

From an ethical point of view, the physical and emotional security of research team members is equally important. In addition, research team coordinators must take into account the diversity, needs, and requirements of research team members by ensuring appropriate working conditions and inclusive approaches.

In order to overcome harm or danger for research team members, it is necessary to know the legal framework, including liability systems, education in the field, discussions with professionals and experienced people, those who have used mental health services, and, if possible, people with such conditions and their relatives. Having a legal framework will help prevent the research team from disclosing information that could result in members being held liable, including defamatory, dishonest, business reputation, and the researcher's obligation to publish sources (which is also dangerous to the source) when reporting about situations containing criminal elements.

### 3.2.2. The Ethical Issues and Risks of Conducting Research with the Participation of Vulnerable Groups

Before, during and after the research, different challenges may arise about reaching, engaging, and treating different research subjects or participants. These individuals are often called vulnerable, which is followed by additional guarantees for the realization of their rights and protection, and (or) vice versa, opportunities for rights interference. Vulnerability is a necessary component of ethical frameworks, which include solidarity, care, and social responsibility.[21] There are no clear criteria for assessing vulnerability as such. Different rules of ethics specify groups or characteristics of individuals that may put individuals in a more vulnerable position during research. Vulnerability of individuals is often formed as a result of being considered

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[21] ten Have H. Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics. J Bioeth Inq. 2015 Sep;12(3):395-408. doi: 10.1007/s11673-015-9641-9. Epub 2015 Jul 10. PMID: 26160601.

"historically vulnerable", in a hierarchical relationship, in a dependent state, or due to specific circumstances. Children, minors or young people, prisoners, people with mental health problems, racial and ethnic minorities, and women are often identified as vulnerable. It is important to remember that these groups are not homogeneous, and some may have multiple vulnerabilities, and the researcher should in any case be guided by the principle of taking an individual approach.

Considering a person vulnerable, no matter what group he or she belongs to, should not lead to depriving him/her control over his/her life and decisions. When involving research participants, it is necessary to consider and take into account their decision to participate in terms of personal choice and from the point of view of public pressure. One should never think that decisions are stable and unchangeable. Situations can change, and a person's decisions to participate in research can change. At the same time, researchers say, the infantilization of research participants, especially those considered vulnerable, can from time to time lead to forms of protectionism that violate the participant's right to making decisions, share his/her approaches, and take informed risks. For example, there are very few studies involving persons with severe or multiple disabilities or a type of disability that, by accepted standards, makes them more difficult to understand. According to researchers, this is a consequence of the work of ethics committees, which try to be "extremely" careful in the case of these people participating in research. However, the question of how the involvement of individuals we "label" as vulnerable may affect the extent and content of our knowledge, as well as how our knowledge of their experience and rights is shaped can be a subject of separate research. Apart from the fact that the consequences of considering a person "vulnerable" should be a separate issue, it is also a question of who has the right to make such a decision.[22]

Maintaining the autonomy of vulnerable persons requires that the right of each person to make decisions about themselves in the research process be taken seriously. However, this does not mean that the research participant should express a purely passive consent to the decisions about him/her. Appropriate mechanisms to help the person in making their decisions must be introduced.

Thus, in terms of participation, representation and inclusion, people, regardless of disability or other manifestations of human diversity, should be able to participate equally as research subjects. This includes the provision of easy-to-read material for adults and children with mental health problems, including the final document, the report, so that participants can learn about the findings, as well as ensuring accessability to materials, means of communication and chosen locations for persons with visual, hearing, mobility impairments and psychosocial and/or mental health problems.

From the point of view of ethical approaches to conducting research on the rights of persons with disabilities and with their involvement, the provisions of the UN Convention on the Rights of Persons with Disabilities are also crucial, in particular the implementation of interrelated principles of respect for rights, consent and confidentiality. These principles are a major factor in all kinds of ethical research on human beings, but they have often been overlooked in research with the participation of people with disabilities.

In any case, it is important to remember that researchers' approaches and attitudes towards people with disabilities began to change only in the 1990s when people with disabilities began to be seen not as objects but as subjects of law. Researchers also will still have a stereotypical attitude. The change in attitudes demonstrates the effectiveness of reducing the involvement of intermediaries or proxies in interactions with

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[22] Santinele Martino, Alan & Fudge Schormans, Ann (2018). When Good Intentions Backfire: University Research Ethics Review and the Intimate Lives of People Labeled with Intellectual Disabilities [31 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *19*(3), Art. 9, *http://dx.doi.org/10.17169/fqs-19.3.3090*. *https://www.qualitative-research.net/index.php/fqs/article/download/3090/4264?inline=1*

people with disabilities, which is becoming possible also due to the use of new data collection techniques, innovative technologies, specialized software and social media.

Ensuring ethical principles requires that researchers carefully plan the research for the following situations:

- When conducting research in care, medical or other types of facilities, where, regardless of whether public or private, the services are provided around the clock or at certain times, for example, it may be difficult to maintain confidentiality.
- In situations where individuals may require intimate and personal care, and there is a danger that the bounderies of the person's immunity are not adequately respected. In such a case, it is desirable to involve the person and inform the relevant authorities about the danger.
- Involve lawyers, translators or proxies as needed to ensure effective communication between researchers and participants. As a general rule, direct contact between the researcher and the respondent is preferable. The decision to involve mediators should be made as a result of an independent and impartial assessment of the situation, the mediator's actions should be kept in focus and be manageable. The mediators must be trained.
- The issue of direct contact with children with disabilities has received special attention in recent years. The involvement of mediators and proxies in dealing with children with disabilities should be minimized as well.
- Consider that persons with psychosocial disabilities and/or mental health problems, being socially more disadvantaged, are more likely to be excluded from research as they may have a lower level of education and employment, as well as be deprived of services and be out of the researchers’ sight.
- Take into account gender factors: The existing stereotypes about women, including women with disabilities, and their additional needs also should be researched.
- In the case of national minorities, take into account their characteristics, restrictions on treatment, rehabilitation, reporting problems, etc.

To maintain research ethics, researchers need to:

- Develop their experience and knowledge, be trained in disability and, in particular, on the rights of people with mental health problems.
- Study relevant examples of positive experiences.
- Consult with other experts if necessary. Be prepared that other people with disabilities who have such experience, family members, friends, as well as specialists in the field can act as such experts.
- Be open to dialogue and different forms and technologies of communication.
- Consider different decision-making methods, in particular in the case of informed consent issues.
- Develop ethical norms for research and in doing so, consult with people with disabilities and specialists in the field.

The ethical competencies required of the researcher working with research participants, research subjects are the emotional intelligence, management of the person's visibility, understanding of the person's forms of self-expression, as well as what consequences it has in enabling the person.

### 3.2.3. Conducting Research with the Participation of Women with Psychosocial Disabilities and/or Mental Health Problems: Additional Tips

The total number of mental conditions is almost the same for men and women, however, different types of conditions prevail in people of one or another gender.

There are no clear gender differences in some mental health problems, such as schizophrenia and bipolar disorder, which affect less than 2% of the population. However, gender differences are especially prevalent in the case of general mental health problems such as depression, anxiety, and somatic complaints. These problems are prevalent among women, one in three women in the world feel the impact of these situations, and they are a serious public health problem.

Unilateral depression is twice as common in women. Depression is not only the most common mental health problem in women, but it can be deeper in women than in men.

Gender risk factors for mental health problems that disproportionately affect women include gender-based violence, socioeconomic disadvantage, low income, and income inequality, inferior or low social status and classification, and responsibility for caring for others.
The high prevalence of sexual violence experienced by women and The corresponding level of post-traumatic stress disorder (PTSD) makes women the largest group of people with this disease.
In different countries and environments, depression, anxiety, psychological depression, sexual and domestic violence, and the increasing rates of drug abuse affect women more than men. Role difference and gender discrimination poverty, hunger, malnutrition, overwork, domestic violence, and sexual violence: these pressures all contribute to women's poorer mental health.
Gender is crucial to the extent to which a woman’s or man's control over her mental health and socioeconomic determinants of life, social status and attitude, as well as exposure to certain mental health risks. Gender stereotypes are present in the treatment of mental health problems. Communication between female patients by health-care workers is extremely authoritarian in many countries, which makes it difficult to identify a woman's psychological and emotional difficulties and often stigmatizes her. While women dare to identify their problems, many health care providers are prone to gender bias which pushes them to either "over-treat" or "under-treat" them. Doctors are more likely to diagnose depression in women than men, even if they have the same standards for standardized depression or have the same symptoms. Women are more likely to be prescribed psychotherapy.

However, the number of accurate data on gender-disaggregated research is extremely low, and more attention needs to be paid to revealing trends in gender-disaggregated research.

With the involvement of women in research, the following ethical issues may arise:

- Women's invisibility, neglect, marginalization, and dependence on other people that increase the risk of negative consequences of participating in the study, especially when reporting violence. To overcome this problem, it may be helpful to involve women's organizations specializing in women's rights with disabilities as partners. Involve mental health issues, women with mental health issues, and women with disabilities as members of the research team, ensuring that they have the accomidations to express their opinions within the team and in safe environment.

- The prejudiced attitude towards women that members of the research team also may be inclined to. It is important that problems be presented accurately, for example, when violence is not justified as an act caused by a woman's behavior.
- Issues of obtaining informed consent can cause additional problems in patriarchal society (a parent, husband, brother, or other persons cannot consent instead of an adult woman).
- Women, including women with psychosocial disabilities and/or with mental health problems, are often reluctant to report cases of violence, especially sexual violence. It is desirable that fieldwork and interviews on cases of violence, including sexual violence, be conducted by female researchers. Focus group discussions on such issues are highly undesirable.
- Women may come in for an interview with their children or other caregivers, or be with them if the interview is in their apartment. Inform about this in advance, assess the situation, the age and maturity of the child, if you think that the examination can affect the child, with the permission of the woman, take care of the child through a partner. In any case, the child should not be exposed to traumatic effects.

### 3.2.4. Conducting Research with the Participation of Children with Psychosocial Disabilities and/or Mental Health Problems: Additional Tips

Children are part of society and have their ideas about the violation of rights.

Involving children in research can help receive information and views that would not otherwise be available. This also enables them to contribute to the development of the law?
According to some experts, the essence of children's rights and their participation in research is debatable, complicated, and, presumably, has been neglected for many years.
The child’s or young person ‘s social capabilities and rights or protection of their interests must be balanced. Specialists have all the opportunities to listen, intervene and support. And it will be more complete through open dialogue with them, consultation, respect for their views and autonomy.[23]
Although children are vulnerable and need extra protection when participating in research, they should not be ruled out altogether as this may be more detrimental to their well-being than their participation. Children should be allowed to participate in research, but with additional safeguards to protect their vulnerability.[24]
International and domestic regulations on the rights of the child are intended to treat children as a full-fledged subject of law, but it is important to note that additional efforts are needed when conducting research with children. Their age, maturity and dependence on other people increase the likelihood of possible harm, as well as the risk of double trauma.

Before planning any action with children, the researcher should carefully evaluate the risks and benefits, such as whether it is justified to interview a child who has been abused, including sexual abuse. It is important to remember that the best interests of the child are paramount; in some situations, interviews with children

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[23] Levine DT, Morton J, O'Reilly M. Child safety, protection, and safeguarding in the time of COVID-19 in Great Britain: Proposing a conceptual framework. Child Abuse Negl. 2020 Dec;110(Pt 2):104668. doi: 10.1016/j.chiabu.2020.104668. Epub 2020 Aug 13. PMID: 32828561; PMCID: PMC7425676.

[24] Gandhi R. Research involving children: regulations, review boards and reform. J Health Care Law Policy. 2005;8(2):264-330. PMID: 16471026. https://digitalcommons.law.umaryland.edu/cgi/viewcontent.cgi?article=1104&context=jhclp

should be avoided altogether. It is necessary to discuss this with specialists, particularly psychologists. There may be a need to involve a mediator (psychologist, parent). It is not advisable to interview a child who is still in a state of stress.

When involving children in research, it is necessary to take into account and assess the nature and the degree of that involvement, to choose from the range of research methods the ones that will be most harmless and effective for children of that age, maturity, enabling the very young children, as well as children with various mental-health problems, various mental-health states and support needs, to realize their right of participation. It is important that researchers be willing to show patience, use creative approaches to make methods accessible to children, as well as to meet the children's  communication preferences and expectations. It is also important that researchers assess their expectations from the involvement of children accurately.

Thus, when involving children:

- The primary principle should be not to harm and to take into account the best interests of the child.
- It is desirable to discuss with specialists the most effective means and methods of working with a child with a disability of a given age and maturity and.
- It is advisable not to interview a child who is still traumatized, especially when the risk of re-traumatization is high. It is necessary to assess the child's injuries, mental state and the use of mitigation measures in advance.
- Publish the child's personal data, even with the consent of the child and the parent, only in case of extreme necessity.
- Always ask for the informed consent of the child when taking any action.

**References Used in Developing this Section**

*Legal Documents*

51. UN Convention on the Rights of Persons with Disabilities, March 30, 2007 https://www.arlis.am/DocumentView.aspx?DocID=64762
52. General comment No. 1. Article 12 of the CRPD: Equal recognition before the law. (2014). Committee on the Rights of Persons with Disabilities. https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en
53. General comment No. 2. Article 9 of the CRPD: Accessibility. (2014). Committee on the Rights of Persons with Disabilities. https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/2&Lang=en
54. The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Convention on Human Rights and Biomedicine, April 4, 1997 https://drive.google.com/file/d/1QN0Iki9kFeu1Gli1Y8xsqpPho_Q2AFg6/view?usp=sharing
55. Explanatory Report to the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. Oviedo, 4.IV.1997. https://rm.coe.int/16800ccde5
56. UN Convention on the Rights of the Child, November 20, 1989 https://www.arlis.am/DocumentView.aspx?DocID=60503
57. General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24) of the CRC. Committee on the Rights of the Child. https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f15&Lang=en
58. General comment No. 20 (2016) on the implementation of the rights of the child during adolescence. Committee on the Rights of the Child. https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f20&Lang=en
59. Constitution of the Republic of Armenia, December 6, 2015 https://www.arlis.am/DocumentView.aspx?DocID=143723
60. RA Law on the Rights of Persons with Disabilities, No. ZR - 194 May 5, 2021, https://www.arlis.am/DocumentView.aspx?DocID=152960
61. RA Law on Personal Data Protection, No. ZR - 49 https://www.arlis.am/DocumentView.aspx?DocID=132745
62. RA Law on Mental Health Care, No. ZR - 80 https://www.arlis.am/DocumentView.aspx?DocID=146066

63. RA Law on the Rights of the Child, No. ZR - 59, 29.05.1996. https://www.arlis.am/DocumentView.aspx?DocID=149836
64. RA Law on Medical Care and Service to the Population, No. ZR -42.
65. RA Law on repealing the decision No. 63 January 24, 2002 and on approving the issuing permits for clinical trials, the examination procedures carried out for that purpose, and the lists of required documents https://www.arlis.am/DocumentView.aspx?DocID=128876
66. Based on the application of the Human Rights Defender, Article 7, Part 3, Article 8, Parts 3, 4, Article 17, Part 2 of the RA Law on Medical Care and Services to the Population , Article 19.3, Part 1, Clause 4, Article 6, Part 10 of the RA Law on Psychiatric Care, Article 9, Parts 1 and 2, Article 15 and 16 Article 19, Part 2, Part 3, Parts 4, Article 22, Part 1, Paragraph 2, Paragraph 4 of Annex 6 to the same law and "On the Rights of the Child" Article 32, Part 2 of the Law on Determining the Issue of Compliance with the Constitution of the RA Constitutional Court, 2020 Decision No. DCC-1504 of January 30. https://www.arlis.am/DocumentView.aspx?DocID=138724
67. "On the basis of the application of the RA Human Rights Defender, on the case of determining the issue of compliance of the RA Civil Procedure Code with the second sentence of Article 171, Part 1, Article 173, Part 1 of the RA Constitution" of the RA Constitutional Court 2015. Decision No. DCC-1197 of April 7. https://www.arlis.am/DocumentView.aspx?DocID=96759
68. Case of Nikolyan v. Armenia. Application no. 74438/14. October 03, 2019. https://hudoc.echr.coe.int/eng?i=001-196149

*Guides and Manuals*

69. “Socies Expert Centre”, DATA Partners (2021). Ethical guidelines for social research. practical guide. Yerevan “DATA. Data for Accountable and Transparent Action” Program
70. Handbook of Research Ethics and Scientific Integrity. Ron Iphofen Editor. 2020. Springer, Cham. https://doi.org/10.1007/978-3-030-16759-2_30
71. Resnik, David. (2018). The Ethics of Research with Human Subjects. 74. doi:10.1007/978-3-319-68756-8.
72. Disability-Inclusive Child Safeguarding Toolkit. Able Child South Africa. Safe the Children. 2021. https://resourcecentre.savethechildren.net/pdf/disabiltiy-inclusive-child-safeguarding-toolkit.pdf
73. The European Charter for Researchers. https://euraxess.ec.europa.eu/jobs/charter/european-charter
74. Ethics in Social Science and Humanities. https://ec.europa.eu/info/sites/default/files/6._h2020_ethics-soc-science-humanities_en.pdf
75. OECD (2016-11-08), “Research Ethics and New Forms of Data for Social and Economic Research”, OECD Science, Technology and Industry Policy Papers, No. 34, OECD Publishing, Paris. http://dx.doi.org/10.1787/5jln7vnpxs32-en https://www.oecd-ilibrary.org/docserver/5jln7vnpxs32-en.pdf?expires=1636063268&id=id&accname=guest&checksum=2306F2239E3D982D1067DCD5F6B2FE9F

76. International Ethical Guidelines for Health-related Research Involving Humans, Fourth Edition. Geneva. Council for International Organizations of Medical Sciences (CIOMS); 2016. https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf
77. Nuremberg Code. [From Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No 10 Nuremberg, October 1946-April 1949. Washington D.C. U.S. 1949-1953]. Permissible Medical Experiments. August 19, 1947. https://www.ushmm.org/information/exhibitions/online-exhibitions/special-focus/doctors-trial/nuremberg-code
78. The Belmont Report. Ethical Principles and Guidelines for the Protection of Human Subjects of Research. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html
79. Gender and women's mental health. WHO https://www.who.int/teams/mental-health-and-substance-use/gender-and-women-s-mental-health

*Research Materials*

80. Levine DT, Morton J, O'Reilly M. Child safety, protection, and safeguarding in the time of COVID-19 in Great Britain: Proposing a conceptual framework. Child Abuse Negl. 2020 Dec;110(Pt 2):104668. doi: 10.1016/j.chiabu.2020.104668. Epub 2020 Aug 13. PMID: 32828561; PMCID: PMC7425676.
81. Veatch, R. M. (2020). Reconciling Lists of Principles in Bioethics. The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine. doi:10.1093/jmp/jhaa017
82. Shea, M. (2020). Forty Years of the Four Principles: Enduring Themes from Beauchamp and Childress. The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine, 45(4-5), 387–395. doi:10.1093/jmp/jhaa020
83. “Introducing a Human Rights-based Disability Research Methodology” Arstein-Kerslake, A., Maker, Y., Flynn, E., Ward, O., Bell, R., & Degener, T. (2020). Introducing a Human Rights-based Disability Research Methodology. Human Rights Law Review. doi:10.1093/hrlr/ngaa021. https://academic.oup.com/hrlr/article-abstract/20/3/412/5899175?redirectedFrom=fulltext
84. Cohen, S. (2018). The logic of the interaction between beneficence and respect for autonomy. Medicine, Health Care and Philosophy, 22(2), 297–304. doi:10.1007/s11019-018-9876-4
85. Santinele Martino, Alan & Fudge Schormans, Ann (2018). When Good Intentions Backfire: University Research Ethics Review and the Intimate Lives of People Labeled with Intellectual Disabilities [31 paragraphs]. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 19(3), Art. 9, http://dx.doi.org/10.17169/fqs-19.3.3090. https://www.qualitative-research.net/index.php/fqs/article/download/3090/4264?inline=1
86. Van der Heijden, I., Harries, J., & Abrahams, N. (2018). Ethical considerations for disability-inclusive gender-based violence research: Reflections from a South African qualitative case study. Global Public Health, 1–13. doi:10.1080/17441692.2018.1542
87. Eileen Carey & Colin Griffiths (2017) Recruitment and consent of adults with intellectual disabilities in a classic grounded theory research study: ethical and methodological considerations, Disability & Society, 32:2, 193-212, DOI: 10.1080/09687599.2017.1281793

88. Steinert, C., Steinert, T., Flammer, E. et al. Impact of the UN convention on the rights of persons with disabilities (UN-CRPD) on mental health care research - a systematic review. BMC Psychiatry 16, 166 (2016). https://doi.org/10.1186/s12888-016-0862-1
89. Triple jeopardy: Ethical considerations in researching violence against women with disability in Cambodia. Joanne Crawford and Ann Maree Nobelius, International Women's Development Agency (IWDA) and Joanne Webber, CBM Australia. February 2015https://acfid.asn.au/sites/site.acfid/files/resource_document/Triple-Jeopardy.pdf
90. ten Have H. Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics. J Bioeth Inq. 2015 Sep;12(3):395-408. doi: 10.1007/s11673-015-9641-9. Epub 2015 Jul 10. PMID: 26160601.
91. The Convention on the Rights of Persons With Disabilities: A Foundation for Ethical Disability and Health Research in Developing Countries. Jo Durham, PhD, Claire E. Brolan, MA, and Bryan Mukandi, MD. Am J Public Health. 2014 November; 104(11): 2037–2043. Published online 2014 November. doi: PMCID: PMC4202975. PMID.
92. Haugen HM. Inclusive and relevant language: the use of the concepts of autonomy, dignity and vulnerability in different contexts. Med Health Care Philos. 2010 Aug;13(3):203-13. doi: 10.1007/s11019-010-9242-7. PMID: 20383588.
93. Gandhi R. Research involving children: regulations, review boards and reform. J Health Care Law Policy. 2005;8(2):264-330. PMID: 16471026. https://digitalcommons.law.umaryland.edu/cgi/viewcontent.cgi?article=1104&context=jhclp
94. Ruof MC. Vulnerability, vulnerable populations, and policy. Kennedy Inst Ethics J. 2004 Dec;14(4):411-25. doi: 10.1353/ken.2004.0044. PMID: 15812988.

# Abbreviations and Definitions

| | |
|---|---|
| RA | Republic of Armenia |
| UN | United Nations |
| CRPD | Convention on the Rights of Persons with Disabilities |
| Oviedo Convention | Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine<br>Convention on Human Rights and Biomedicine |
| Safe space | a place or environment in which a person or category of people can feel confident that they will not be exposed to discrimination, criticism, harassment, or any other emotional or physical harm. |
| Child | any person under the age of 18.<br>Infantry - 0-1 years<br>Early childhood - 1-3 years<br>Preschool age - 3 - 6 years<br>School age - 6-10 years<br>Adolescence - 10-18 years (early adolescence - ages 10 to 13, middle adolescence - ages 14 to 16, late adolescence - ages 16 to 18) |
| Sample | Population under certain research. |
| Bias | Prejudice, baseless assumption about a person, groups of people. |
| Persons with disabilities | Persons who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. |
| Persons with psychosocial disabilities and/or mental health problems | Persons who have long-term mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. |

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|---|---|
| Accessibility | For persons with disabilities, on an equal basis with others, access to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas, with the aim of enabling persons with disabilities to live independently and participate fully in all aspects of life. |
| Participatory | Enabling and ensuring personal participation. |
| Methodology | Theory or analysis of how research is and should be done. |
| Method | A systematic approach to the implementation of an action or a process, including procedural steps, use of techniques, causal or analitical systems and research methods used in the given scientific field. |
| Hypothesis | A scientific assumption put forward to discover or interpret a phenomenon. |
| Data | Factual material commonly accepted in the scientific community as necessary to validate research findings'. |

# For Notes