

The meaning and value of participation in health promotion and prevention

Possibilities, Challenges, Chances

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„Determinants of health model – Rainbow“ Dahlgren & Whitehead (1991)



Participation is a precondition for **Inclusion**

Inclusion (sociological definition) =

Society, in which everybody (independent from age, sexual orientation, religion, nationality, social status, handicap) is accepted equally and able to participate with equal rights

(Schöb 2013)

What does **participation** mean?

- Participation targets at the creation of positive social changes
- You cannot separate social realities from health issues
- Participation means that people/excluded/vulnerable groups are involved in health promotion and prevention in different ways in order to improve the quality of the approaches/change the approaches and in order to have a positive influence on their living conditions and life styles
- Participation is the defining principle throughout every single process

(Compare also: Wright, Michael T. et al (2013): ICPHR Position Paper No. 1: What is Participatory Health Research?)

Participation

- might, will and must be understood differently.
- It depends on your context, on your targets, on your knowledge, on your interests and the interests of others involved
- It will remain an unclear definition until you define it together with those you are working with

Because what does/can participation mean for

- ❖ you **personally**
- ❖ your **colleagues**
- ❖ your **organisation**
- ❖ your **boss**
- ❖ your **sponsor**
- ❖ your **government agency**
- ❖ **the groups you are working with**, for example
Roma communities and their families or
drug users who are excluded in many ways all over Europe?
- ❖ What does it mean in a **therapeutical context?**

Participation is not new!

- **Education and many fields of social work**
(Theater education; youth work; literacy programs by Paulo Freire, where the focus is **on the learning and education of all participants in a participatory process**)
- **Development cooperation in the Global South**
(project partners are included in the planning and establishment of programs and projects from the very beginning)
- **Established forms of participation in different cultures**
(For example: „Minga“ in Latin America;
Sou-Sou-Saving Clubs in West African countries = jointly owned saving plans)
- **Science and Research**
(Action Research by Kurt Lewin;
today, there are many different characteristics based on historical, political, cultural or regional situations such as Participatory Health Research, Community Based Participatory Research etc.)

Which preconditions are needed for participation?

- **Attitude/position** (the will to include individuals, communities, authorities in developing ideas, concepts, approaches, prevention messages; share responsibilities; question power structures)
- The will to **self-reflection**, process reflection
- The will and courage to **change point of views** (your own view, your organisation's view, re-distribution of financial and personal resources)

Participation also needs

- **a frame (Example „detention center Austria“, focus on prisoners and prison staff, no political approach)**
- **common goals** (can always be changed)
- **questions of participation** (who can, who shall, who need to be included and in which ways)
- **transparency** (different forms)
- **definitions** (For example: How do we understand „participation“? How do we understand „health“? How do we understand „empowerment“ or „vulnerability“?)
- **negotiation processes** and the **willingness for compromises among all participants**

 **based on your context**

Approaches and ways to start participatory processes

- are manifold
- depend on your possibilities
- depend on your time
- depend on your financial resources
- depend on your target (do you want to do prevention or do you want political changes; do you want both?)
- depend on which people, organizations etc. should be included

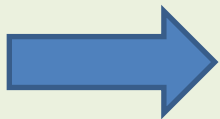
According to Cornwall & Jewkes (1995)

- a basic difference between conventional and participatory approaches lies in the change of power structures within the different processes
- Characteristic for participatory approaches is the methodological context rather than methods themselves (Example African social worker working with African communities)

Do participatory approaches need special methods?

All known and new methods can be used in a participatory way

- **Research methods** (qualitative und quantitative methods; explicitly „partizipative methods“, for example „**Photovoice**“, „**Community Mapping**“, **Focus groups**)
- **Learning and educational methods** (scholars are included in topics)
- **Methods of action** in social work (individual help, work in groups, counselling, community work)



Include target groups to discuss and shape these methods

There are many challenges if you choose participatory approaches

- (1) Political barriers and contradictions
- (2) Work with different actors, participants
- (3) Ethical aspects (relationships, great expectations)
- (4) Institutional realities and constraints

(1) Political barriers and contradictions

- are different in all European countries
- are even different in regions
- depend on groups and communities (legal rights, grade of exclusion and discrimination, racism, vulnerability = to be discussed)

(2) Participatory approaches with different actors, participants

Example: Working with drug users

(1) Broad spectrum of drug users

(2) Families, partners

(3) Drug counselling service (colleagues and structures)

(4) Public administration (dependent on political decisions, hierarchy)

(5) Politicians

(3) Ethical aspects

- There are many new ethical aspects, especially when you work with „vulnerable“ groups based on the idea of participation
- **Empowerment** but lack of power (see Narimani 2014)
- **New forms of relationships**
- **Responsibilities** (f.e.: Through **participation** you try to be equal, however, as a social worker you normally have more power than the groups you are working with, this does not change; there is always a gap between paid staff and voluntary work of the „vulnerable“ groups involved)
- **Higher expectations**

(4) Organisational and institutional constraints

- Financial conditions (budget year; financial volume; billing modalities; timelines; „successful“ strategies are expected)
- Social workers and managers of social services are dependant on their organisational, institutional and structural requierements

Chances of participatory approaches (1)

Through participatory approaches and reflection processes

- you start **to question and to discuss decision-making power**
- different **requirements** become visible
- **contradictions within systems** can be seen
- **structural and political violence** become evident (see Becker & Burtscher 2019)
- **support groups (self help)** - which are fundamentally important - can be promoted and further developed (peer approach) => support groups are needed in order to complement offers; should be standardized

Chances of participatory approaches (2)

Through participatory working and reflection processes health promotion and prevention concepts and programs can be strengthened because

- **ALL participants will gain information and knowledge in a common process**
- **responsibilities will be shared**
- **Innumerable possibilities are revealed which you would not have without participation**
- **ethical questions can be discussed and decided in a group**
- **individual (and legitimate) interests of all participants are possibly revealed**
- **Democratic processes and equality in the sense of Human Rights and Social Work will be promoted**

Example

A participatory project with migrant drug users, financed by the German Ministry of Health for 2 years, was evaluated. 7 projects in different German cities were visited and 4 final talks in each project were organized:

- with migrant drug users,
- with social workers,
- with managing directors and bookkeepers
- with all people involved

Questions for everybody: What did you learn? What should be changed? What could be done differently? How can we support each other?

For the first time, drug users could understand the constraints of the managing directors and bookkeepers and vice versa they learnt about the life of drug users. They sat at the table TOGETHER and learnt from each other. They tried to keep up discussing and working TOGETHER.

Why should we choose participatory approaches?

It is about *equality* in a society.
In order to preserve the dignity
of human beings,
it is necessary to form
processes of cooperation/participation
in a fair way.

(Neuhäuser 2019, S. 76-77)

Bring people together – listen to people – discuss and decide together!

Literature and recommendations

- **Becker, Klaus-Peter & Burtscher, Reinhard (2019):** Gemeinsam forschen – Gemeinsam lernen. Menschen mit Lernschwierigkeiten in der Partizipativen Gesundheitsforschung. Stiftung Rehabilitationszentrum Berlin Ost. Berlin: DBM Druckhaus
- **Cornwall, Andrea & Jewkes, Rachel (1995):** What is Participatory Research? In: Soc. Sci. Med. Vol. 41. No. 12. pp 1667-1676. Elsevier Science Ltd.
- **Miko-Schefzig, Katharina & Reiter, Cornelia (2018).** Partizipatives Forschen im Kontext der Organisation Polizei: Ethisches Forschen mit vulnerablen Gruppen am Beispiel der Schubhaft [47Absätze]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 19(3), Art. 10, <http://dx.doi.org/10.17169/fqs-19.3.3142>
- **Narimani, Petra:** Zustimmung als Prozess: Informiertes Einverständnis in der Praxisforschung mit von Ausweisung bedrohten Drogenabhängigen. In: Von Unger, Hella; Narimani, Petra; M'bayo, Rosaline (Hrsg.) (2014): Forschungsethik in der qualitativen Forschung. Reflexivität, Perspektiven, Positionen. Wiesbaden: Springer VS, S. 41 - 58
- **Neuhäuser, Christian (2019):** Wie reich darf man sein? Über Gier, Neid und Gerechtigkeit. Stuttgart: Reclam, Universal-Bibliothek
- **Schabdach, Michael (2009):** Soziale Konstruktionen des Drogenkonsums und Soziale Arbeit. Historische Dimensionen und aktuelle Entwicklungen. Wiesbaden: VS Verlag
- **Schöb, Andrea (2013):** Unter: www.inklusion-schule.info/inklusion/definition-inklusion.html. Zugriff am 08.10.2019
- **Wright, Michael T. et al (2013):** International Collaboration for Participatory Health Research, Position Paper No. 1: What is Participatory Health Research?

Links

- **Participatory Project for and with homeless people; videos in different languages:**
https://tropeninstitut.charite.de/forschung/ag_neglected_diseases_and_vulnerable_populations/charite_covid_19_projekt_fuer_und_mit_obdachlosen
- **HIV-Self-Help Groups with and for African People in Germany: AfroLebenPlus:** <https://www.hiv-migration.de/netzwerke/afrolebenplus>
- **Participation and cooperation in HIV prevention with migrants in Germany (PaKoMi):** <https://www.hiv-migration.de/content/pakomi-handbuch-deutsch>
- **Drug Prevention for and with Migrants in Germany (PaSuMi):**
<https://pasumi.info/>