

# Participatory Quality Development in HIV Prevention

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# Levels of Participation

Based on our own research and following Sherry Arnstein's work (Participation), we have developed a staged model to better describe the characteristics of participatory processes that already exist within health promotion and prevention. Service providers can apply this model to e.g. assess the degree of participation they have already achieved within their activities and to develop options to increase it further (see also *Circles of Influence*). It is our view that participation is not an "either/or" decision but a developmental process. In many circumstances certain precursors to participation have to be implemented before a comprehensive inclusion of the target group in decision-making processes becomes possible. Many interventions that call themselves participatory do not offer any opportunities to influence decisions, and can therefore not be classed as such.

Individual levels of participation are explained below using the example of target group involvement:

Many variants are imaginable on the non-participatory level. Here we describe two types frequently encountered in the fields of health promotion and prevention:

# Level 1: Instrumentalisation

The target group's concerns do play some role. Decisions are made without them and centre on the interests of the decision makers. Members of the target group may participate in events without being aware of their purpose or objectives (target groups as "decoration").

# Examples:

Only those residents in a district who support the views of the decision makers are asked for their opinions. The results of such a survey are reported as the opinions of all district residents. Or: small children are used in political rallies to convey the positions of their parents without being able to understand the nature of the event themselves.

# Level 2: Instruction

Decision makers (often professionally trained personnel) take note of the target group's situation. They define the problems and the responses to resolve or mitigate these problems exclusively on the basis of their (expert) opinions. The target group's views of their own situation are not taken into account. Communication on the part of the decision makers is directive.

# Examples:

Many conventional forms of medical, psychotherapeutic, educational or social work counselling and treatment are characterised by the fact that professionals carry sole responsibility for defining (diagnosing) the problem as well as choosing the solution. Such professionally determined interventions are often necessary, e.g. in cases of imminent danger (disease, child abuse) or where the options available to those affected are restricted (e.g. limited decision-making competency, as in young children or in certain crisis situations).

Precursors to participation include the increasing integration of the target group into decision-making, even if they cannot (yet) influence its processes directly.

# Level 3: Information

Decision makers tell the target group about its problems (from the point of view of the decision makers) and what kind of assistance they require: They recommend to the target group options to resolve or mitigate their problems. The decision makers explain and give



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reasons for the process they use and the information they provide. They take the views of the target group into account in order to promote target group member acceptance of the information and the retention of the messages provided.

# Example:

Conventional health education activities generally fall into this category. Whether as part of a national campaign or within the context of training programs, at the forefront is the conveying of information as adapted and presented by experts.

# Level 4: Consultation

Decision makers are interested in how the target group sees their own situation. Members of the target group are consulted, but have no control over whether their views are taken into account.

# Example:

The consultation strategy most often employed in health promotion and prevention practice is the survey. Whether conducted orally or in writing, through individual or group interviews, the survey is intended to elucidate the target group's situation by asking them a set of questions. Individual or group responses are normally reported anonymously and combined with the views of others to arrive at an overall picture of the target group's circumstances.

#### Level 5: Inclusion

The service organisation asks selected members of the target group for advice (these are often persons close to the decision makers). The advice received, however, is not quaranteed to influence decision-making.

#### Example:

In considering the establishment of a new service, a service organisation contacts a migrants' organisation for more detailed information on the situation of young women from the relevant cultural background. A representative from a group for single mothers is invited to a board meeting to report on the needs of women in her situation.

In "true" participation, the target group has a formalised, guaranteed role in decision-making.

# Level 6: Shared Decision-Making

Decision makers consult target group representatives to agree with them on substantive aspects of an intervention. On important questions, negotiations between target group representatives and decision makers may be necessary. Members of the target group have a right to be heard, but no independent authority to make decisions.

# Examples:

The membership of target group representatives on a decision-making committee (board, advisory group, steering committee) is one example of shared decision making. The establishment of a Service User Advisory Committee consisting exclusively of members of the target group is another. Formal collaborations with organisations representing the interest of the target group can also enable shared decision-making.

# Level 7: Partial Delegation of Decision-Making Authority

A right to participation ensures that the target group can determine particular aspects of the intervention themselves. Responsibility for the intervention, however, remains in the hands of others, e.g. personnel of the service organisation.

# Examples:

A service organisation wants to make a sexuality education video for young people and asks



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a youth group to develop the content. A group of volunteers from the target group is formed whose task it is to develop and implement new services for the target group (peer-based model). For example, the service organisation convenes a group of sex workers to raise awareness of Sexually Transmitted Infections (STIs) among other sex workers. The volunteers determine how best to achieve this objective and are supported by the service organisation to put their ideas into practice.

# Level 8: Decision-Making Authority

Members of the target group determine all substantial aspects of an intervention. This takes place within the framework of an equal partnership with the service organisation or other stakeholders. Stakeholders outside the target group also participate in making important decisions, but their role is to support or advise, not to determine.

# Examples:

A Service User Advisory Committee within a service organisation suggests a new service for the target group and takes responsibility for planning and implementing it.

Women in a residential district would like to organise a cooking course and a service organisation provides them access to kitchen facilities.

A migrants' organisation makes contact with an AIDS service organisation to garner their support for developing information sessions in mosques.

The top level of the model goes beyond participation. It includes all forms of selforganised intervention that are not necessarily the result of a participatory developmental process, but can be initiated by citizens themselves from the beginning.

#### Level 9: Community-Owned Initiatives

An intervention or project is initiated and implemented by members of the target group themselves. Such initiatives are often organised by those who are directly affected by a problem. The target group makes decisions independently and takes responsibility for them. Responsibility for implementation also rests with the target group. All decision makers are members of the target group.

# Examples:

This level includes all types of initiatives that are conceptualised and implemented by members of the target group themselves. They may be organised formally (e.g. as a not-for-profit organisation) or informally: as the (spontaneous) action of like-minded people.

# Continue with:

- Further Reading on Participation
- Circles of Influence
- Service User Advisory Committee

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