

# ‘NOTHING ABOUT US, WITHOUT US’

Participation and involvement of drug users  
in health services and policy making

Katrin Schiffer

# Colophon

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**Authors:  
Katrin Schiffer, Correlation-European Harm Reduction Network**

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**Publisher:  
De Regenboog Groep/  
Correlation-European Harm Reduction Network  
Stadhouderskade 159  
1074BC Amsterdam  
Netherlands**

**[administration@correlation-net.org](mailto:administration@correlation-net.org)  
[www.correlation-net.org](http://www.correlation-net.org)**



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***“We are people from around the world who use drugs. We are people who have been marginalised and discriminated against; we have been killed, harmed unnecessarily, put in jail, depicted as evil, and stereotyped as dangerous and disposable. Now it is time to raise our voices as citizens, establish our rights and the right to be our own spokespersons, striving for self-representation and self-empowerment.”***

Statement by The International Activists who use drugs 30 April 2006,  
Vancouver, Canada

## Summary

There is an increasing tendency to get service users, such as Drug Users (DU's) involved in health services and health policies. Participation is seen as an indispensable ingredient for good and effective policymaking and there exist numerous best practice examples of peer involvement in the field of health promotion and prevention. Health policies and health interventions are considered to be more effective and supported, when all relevant parties and communities (including civil society and the final target group) are being involved equally. In addition, policy makers and professionals realise that it is no longer appropriate to talk about and not with the final target group. All kind of communities and also DU's demand their rights: they want to be heard and they want to be taken serious.

There are numerous ways and forms of participation and also the purpose varies from case to case. One could think of information sharing and consultation or focus on empowerment and joint decision-making. Saying this, it can be assumed, that participation is not only a tool and a method, but also a process and a principle.

Yet there are numerous drawbacks which jeopardize the process and make it difficult to respond appropriately. DU's are often poorly represented in service provision and decision making, although there is evidence that their knowledge and expertise is important and most useful for the development of tailored responses and policies.

This paper identifies the facilitators and barriers, which contribute to or jeopardise the process of DU participation. Various participation models and ideas are investigated and the applicability of these models is critically assessed. Last, but not least a more flexible approach – a roadmap for participation - is being introduced, taking into account the relevant determinants and factors in the field. This roadmap will be descriptive, rather than prescriptive, provides guidance and will support the participation process on various levels.

# 1 Introduction

## 1.1. Background

The issue of service user involvement became increasingly important in the past years. Recent health service reforms and health strategies emphasize the need and the necessity to involve service users, when it comes to the development and provision of services and policy making. It is indicated, that the effectiveness of health policies increases when DU's – as the final target group – are involved in the process of policy making. For the development of health interventions there is clear evidence that the involvement of peers 'have a positive result in providing services', because they do have 'inside knowledge' and 'bring credibility and trust' towards an agency<sup>1</sup>. Furthermore participation contributes to the empowerment of DU's, building on the capacities and clearly emphasizing the principles of community, mutuality and equality.<sup>2</sup>

Thus, participation has a positive impact on the development and the impact of services and health policies. But: what about the participation of vulnerable and marginalised groups, such as drug users, who are – generally speaking – mostly excluded from any form of citizen power<sup>3</sup>?

The various sources of information and literature show that DU's are still poorly represented in decision making organs and within services and that their level of influence is relatively low. They are most often seen as part of the problem, but not as part of the solution. And although there are numerous successful drug user organisations (DUO's) and best practice examples of participation with DU's on national and international level, we must conclude that both service providers and policy makers do not always put enough effort into getting this group actually involved<sup>4</sup>.

## 1.2. Problem definition

When we look closer at the process of policy making and the influence of drug users on this process, problems and shortcomings can be identified on various levels.

On the policy making level: many national governments, as well as European and international bodies, have failed to include marginalised DU's when developing health policies, which directly affect them. Participation procedures are often unclear and decision-making processes are not transparent. Consequently, DU's often don't feel heard.<sup>5</sup>

On the level of service provision: service providers are becoming increasingly aware that DU involvement is a challenge, which they need to respond to. Yet, there is the notion that DU involvement is a time consuming and sometimes even disrupting process whilst it is questioned, whether all these efforts are worthwhile. Meaningful DU participation crucially depends on the will and the readiness of services to really involve peers, to create an enabling environment for this process and to prepare the process in cooperation with the target group.<sup>6</sup>

On the level of DU's: DU's live within a certain social vacuum, due to stigmatisation and social exclusion. Some of them may lack the social, material and organisational capacities, as well as the resources and skills to actively participate in the decision making process.<sup>7</sup>

In addition it needs to be acknowledged that not all DU's want to participate, not all DU's are able to participate, not all DU's dare to participate and not all DU's have to participate.

On the response level: there are several participation models and theories, simply depicting how the

1 Toronto Harm Reduction Task Force: Peer Manual, Toronto, 2003

2 Trautmann, F.; Barendregt, C.; European Peer Support Manual, Trimbos Institute, 1995

3 DrugScope; Vulnerable Young People and Drugs: Opportunities to Tackle Inequalities. DrugScope, London.

4 Empowerment and self organisation of drug users, Correlation Network, 2008

5 Correlation Network; Making voices heard – study on access to health and social services for substance users, Amsterdam, 2008

6 What is the evidence on effectiveness of empowerment to improve health? WHO Regional Office for Europe's Health Evidence Network (HEN); February 2006

7 A research into the participation of drug users organisations in the design of drug policies on a local and European level, ENCOD, 2009

participation and involvement process works.<sup>89</sup> These models are often one-dimensional, mainly looking into the issue of power relationships between the 'haves' and the 'have-nots' (Arnstein, 1969). These approaches are useful to define and identify various levels of participation, but they do not contribute to the understanding that various purposes of participation levels require and justify different levels of influence and power.

### 1.3. Objectives and methods

This paper aims to identify barriers and facilitators during the participation process, by analysing various determinants during the implementation process. Based on this analysis, a more specific approach will be suggested, building on a number of existing participation models and theories.

This paper aims to answer the following questions:

- ➔ Why is it important to guarantee involvement and participation of drug users?
- ➔ How can we improve the involvement and participation of drug users and increase the impact of this process on services and the decision making process?
- ➔ Which determinants are responsible for the lack of involvement and participation of drug users?
- ➔ Which strategies and models are currently being used to stimulate involvement and participation of drug users in policy making and the provision of health services?
- ➔ What are the limitations of these models?
- ➔ How can these strategies be improved and adapted to the specific needs of DU's?

I wish to identify the obstructing and the stimulating factors for an effective participation process. I will consult experts in the field and explore the feasibility of various participation models. Last but not least, I want to plead for an impacting health policy in which drug users play an integral part in the policy making process.

The paper is based on a detailed literature review of articles and research reports. I have actively joined various consultation meetings during the Harm Reduction Conference in Liverpool (2010) and in Beirut (2011), as well as the Correlation Peer Seminar, which was held in Prague in 2010.

Additionally, I have consulted and interviewed a number of experts in the field, such as Ingeborg Schlusemann (Director of the Regenboog Groep in Amsterdam), Eberhard Schatz (Correlation Network), Matthew Southwell (INPUD), Jason Farrell (Consultant), Berne Stålenkrantz (Chairman of the Drug User Union in Sweden), Fabrice Olivet (Director of the Drug User Union in France) and John-Peter Kools (Independent consultant, the Netherlands).

8 Wilcox, D. ; The guide to effective participation; [www.partnerships.org](http://www.partnerships.org) ; 1994

9 Arnstein, Sherry R.: A ladder of Citizen Participation, JAP, Vol 35, No 4, July 1969, pp.216-224

# 2 Context analysis

The lack of drug user involvement in the policy making process and the provision of services can be identified during the preparation and the actual implementation of the participation process. In this context, participation can also be seen as innovation, often obstructed by critical factors on various levels. To get a more detailed overview on the contributing facilitators and barriers the generic innovation model of Fleuren e.a. [2004, 2006] is being used. This model helps assessing critical factors and determinants for the implementation of innovations and contributes to more effective implementations in the field. The assessment distinguishes various levels: the policy level, the organisational level, the individual level and the level of the innovation – the participation process itself.

## 2.1. Policy level

The policy level assesses barriers and critical factors in the policy environment and the legal framework.

In many countries in Europe laws and regulations have created a supporting framework for the participation of service users. This applies to decision making within services (e.g. client councils), as well as to external decision making processes (e.g. civil society forums, community working groups, advisory boards).

This development is due to an important social paradigm change in the past two decades: from a more patronizing public health model, based on hierarchical elements and infinite trust in public health professionals, towards a more pluralistic and democratic model with civil society participation as the main element. As a consequence, 'self-help' groups and patient groups entered the policy arena and public health professionals lost their status as 'untouchables'<sup>10</sup>. Time for new strategies with more dialogue and a bottom-up approach.

Despite these positive developments, we must conclude that the involvement of drug users within services is seriously lacking, specifically when it comes to transparency in regard to the status and the mandate of user groups<sup>11</sup>, in regard to the level

of commitment<sup>12</sup> and in regard to the impact of DU participation<sup>13</sup>.

Drug users are still poorly represented when it comes to external decision making processes on local, national and international level<sup>14</sup>. Most often NGO's or GO's are expected to articulate the interests of DU's, without even questioning whether these organisations have the moral right to represent DU's in the policy arena.

Taking this into account, it can be argued that the public health is insufficiently relating to the developments in the field, especially when it comes to strongly marginalised and stigmatised groups such as drug users. Therefore, it is essential to respond to the increasing empowerment of marginalised service users and to develop new ways and strategies, based on the principle of pluralism and democracy.

## 2.2. Organisation of key players

This level of the assessment examines the organisational aspects, based on the various key players, which are individual Drug Users (DU's) and Drug User Organisations (DUO's), Service Providers, involving DU's on a policy level or on a practical level and last but not least policy and decision makers, which organise exchange and consultation processes with DU's.

Interest groups and drug user organisations (DUO's) exist in many European countries. However they rather differ in nature and in the way they deal with participation and interest representation. Anker, e.a. [2008] suggests a certain resemblance with the social movement, observing at the same time that single drug user organisations lack the "broad collective action that challenges existing relations of power."<sup>15</sup>

10 Horstman, Klasien: Mobiliseer de dikkerds, de rokers en de drinkers, Volkskrant, 11 July 2010

11 Wilcox, David: the guide to effective participation, Housing Summary 4, August 1994

12 A research into the participation of drug users organisations in the design of drug policies on a local and European level, ENCOD, 2009

13 What is the evidence on effectiveness of empowerment to improve health? WHO Regional Office for Europe's Health Evidence Network (HEN); February 2006

14 Empowerment and self organisation of drug users, Correlation Network, 2008

15 Drug Users and Spaces for Legitimate Action; Empowerment and Self-Organisation of Drug Users – Experiences and lessons learnt; Correlation Network; 2008

On a national level DUO's often feel as lonesome defenders. This sometimes leads to networking and cooperation among interest groups. In Sweden a number of self-help organisations - representing DU's, sex workers and homeless people – have united in order to become more visible and less isolated, using the common and binding slogan “Nothing about Us, without Us”.<sup>16</sup>

On a European or international level, DUO's have become more visible in the past years. This is partly due to the development of the International Network of People Who Use Drugs (INPUD). The coordinator of the network is one of the 10 NGO delegates of the UNAIDS PCB (Programme Coordinating Board) and this can be considered a milestone in the history of drug user involvement. This example also illustrates that ‘the whole is greater, than the sum of its parts’. One user organisation on the national level may be able to move things forward, but all national organisations together – united in one international network – may already be considered as movement.

The development and survival of user-organisations strongly depends on the input and the long-term commitment of individual DU's. Very often this group of active DU's consists of one or two more or less experienced ‘leaders’, supported by additional volunteers. Their input and enthusiasm keeps the ball rolling. However, pressure and insufficient support can easily lead to a collapse, including both individuals and DUO's.

An additional problem in organising DU's is the generation problem. Younger DU's don't identify themselves easily as DU's and don't want to be stigmatised as such. This has resulted in a significant decrease in the number of DUO's in France: from 22 DUO's at the end of the 1990's to no more than 5 at present.<sup>17</sup>

In practice, we often see ‘mixed DUO's’ and interest groups, run and coordinated by DU's and non-DU's

or ex DU's. Mixed DUO's and interest groups can contribute to the sustainability and continuity of services. On the other hand, mixed DUO's might be criticized after a while, especially when non-DU's become predominant within the organisation.

DUO's and interest groups for DU's often are poorly equipped, including a lack of resources and manpower. Without the contribution of volunteers, it is difficult to address the various issues on the local, national and international level.<sup>18,19</sup> Another main holdback of drug user involvement is the lack of capacities and skills among DU's, which often impedes active and impacting participation in political debates and decision-making processes<sup>20</sup>.

Although DUO's might face serious problems in getting started and in maintaining their activities, it should not be forgotten that they also have an important role when it comes to the development and implementation of innovative and daring health and prevention strategies. The needle exchange programme in the Netherlands for example was firstly initiated by a DUO in Amsterdam. None of the other service providers would have dared to introduce such an intervention, which is nowadays one of the most accepted harm reduction strategies around the world. *“We feel the time for our voices to be heard is long overdue. We know that some of the best initiatives in the drug field were first put forward by drug users themselves, who remained anonymous for their own protection. It is often the case in user groups that people need to spend time complaining about the abuse they have suffered as drug users, and rightly so. When a group survives this, the work can begin – and experiences and opinions can be used in the planning and development of services.”*<sup>21</sup>

16 Based on a phone interview on 16 April 2010 with Berne Stålenkrantz, Chairman of the Swedish Drug User Union Svenska Brukarforeningen

17 Based on a phone interview on 8 April 2010 with Fabrice Olivet, Director of the French Drug User Association ASUD

18 Based on a phone interview on 16 April 2010 with Berne Stålenkrantz, Chairman of the Swedish Drug User Union Svenska Brukarforeningen

19 Based on a phone interview on 8 April 2010 with Fabrice Olivet, Director of the French Drug User Association ASUD

20 A research into the participation of drug users organisations in the design of drug policies on a local and European level, ENCOD, 2009

21 Hamilton, Stefanie et al., Getting Drug Users involved – good practice in local treatment and planning, SKODA, 1997

One of the main issues influencing the participation of drug users is the role of decision makers and service providers. They are mostly the ones initiating the participation process and involve drug users in services and in decision making. They most often create the climate and the conditions, in which consultation and participation takes place.

Participation and the involvement of DU's is often considered as a time-consuming and disrupting process. This applies to service providers as well as to policy makers. It is questioned whether these efforts are worthwhile. Does participation really contribute to better policies and practical results? What are the benefits for the organisation and for policy makers?<sup>22</sup>

There is a lack of knowledge when it comes to the organisation of the participation process. Service providers often don't know how to get service users involved or how to set up a client council. There are examples and best practices, but they are seldom documented or evaluated. This makes it difficult to learn from former experiences and replicate best practices.

Decision makers deal with their own problems. There is an increasing demand to involve civil society, although this does not automatically contribute to quick and easy decision making. Participation is perceived as highly ambivalent. By involving additional stakeholders with different interests, decision making becomes more complicated and controversial<sup>23</sup>.

### 2.3. Users/Implementers

This part of the assessment is targeting pitfalls and drawbacks in relation to the individual key players: DU's, service providers and policy makers.

Not all DU's (and this applies particularly to those DU's accessing low threshold services) are ready to get and stay involved. Some DU's might have different priorities – more basic ones – which makes it hard for them to keep going on. Sometimes the health situation

prevents DU's from making a long-term commitment. Finally, the results of social exclusion, might lead to a lack in organisational knowledge, skills and capacities, which prevents DU's to actively participate in the long term<sup>24</sup>.

The involvement and participation in the decision making process also has personal implications for the individual DU. To 'come out of the closet' also means to be labelled as DU with all consequences for the personal life, the family and the economic situation.<sup>25</sup>

In other words: not everyone wants to participate, not everyone is able to participate, not everyone dares to participate and not everyone has to participate.

Within organisations other problems may occur. While the management may be a profound supporter of the participation of DU's, practitioners might experience the involvement of DU's as a threat. It can also be the other way around: frontline workers push the management for more DU involvement, but the management is not ready to open the dialogue in a serious way, which finally leads to disappointing results and frustrations<sup>26</sup>.

In the perception of policy makers – most often quite detached from the reality at frontline level – DU's are either seen as object of public order or as object of public health, as criminals causing public nuisance, as patients or victims in need of support and help, but seldom as an equal partner, as someone with their own ideas, with their own interests and with the will and ability to share this with others. The stigma of drug use weighs heavily and blocks effective and committed consultation.

The fact that DU's are currently more often considered as 'patients' rather than as 'criminals' might appear at first sight as a positive development, especially when we take into account that patient involvement

22 Based on a consultation in April 2010 with Ingeborg Schlusemann, Director of the Foundation De Regenboog Groep in Amsterdam, The Netherlands

23 Based on a consultation in April 2010 with Ingeborg Schlusemann, Director of the Foundation De Regenboog Groep in Amsterdam, The Netherlands

24 Hamilton, Stefanie et al., Getting Drug Users involved – good practice in local treatment and planning, SKODA, 1997

25 Based on a phone interview on 8 April 2010 with Fabrice Olivet, Director of the French Drug User Association ASUD

26 Based on a consultation in April 2010 with Ingeborg Schlusemann, Director of the Foundation De Regenboog Groep in Amsterdam, The Netherlands

is becoming a legal prerequisite for the development of health policies. However, as a consequence, DU's are now labelled as patients, victims and addicted persons – unable to take self determined decisions. And so it turns out that the 'medical approach', which sounds much more human than the previous 'criminal approach', has the very same effect as the latter one. "It is like being asked whether we would prefer to be smashed on our head with an iron or a rubber hammer. Being asked like that, we for sure prefer the rubber hammer. But, to be very honest: we would prefer not to be smashed at all."

[Matt Southwell, Chairman of the International Network of People Using Drugs (INPUD) during his presentation at the Urban Drug Policy Conference in Prague in 2010].

#### **2.4. Innovation – the participation process itself**

This part of the assessment describes the critical factors in regard to the design of the participation process.

Some governments, international bodies and agencies decide to set up meaningful and transparent participation<sup>27</sup>. Others organise meetings, which are perceived as empty window dressing, without real intentions to cooperate.<sup>28</sup> Most often however, civil society meetings do not include marginalised service users, such as DU's. For example, the Civil Society Forum on Drugs in the EU, organised by the European Commission, DG Justice, Freedom and Security, involves more than 30 agencies, services and interest groups, while only one Drug User Organisations (DUO's) is represented in this forum.

Participation of DU's might make decision making more complicated, especially at the very beginning. It is necessary to agree on the status, the mandate and the level of influence<sup>29</sup>. If service users and DU's don't know what their role is exactly, it will become difficult to organise meaningful participation. This applies to service providers, as well as to decision makers.

There needs to be sufficient support, on the floor among practitioners, at the management level and also the decision making level. Organisations need to invest time, money and energy into this process. DU's being involved in the participation process want to be acknowledged, not only in words, but also in deeds and last but not least also through financial compensation<sup>30</sup>.

Although there is a clear mandate to implement participation of DU's, little is known about the impact of participation on the effectiveness of policies and services. If monitoring is taking place, it is most often focusing on the process rather than the outcome<sup>31</sup>. Documentation is generally poor, although this is needed to share knowledge and replicate best practice examples. This applies also to policy and decision making bodies, which often reinvent the wheel. Example: the various Directorates within the EC, which do have various civil society forums, all of them organised in a different way.

27 [http://ec.europa.eu/health/ph\\_threats/com/aids/aids\\_csf\\_en.htm](http://ec.europa.eu/health/ph_threats/com/aids/aids_csf_en.htm)

28 <http://www.encoded.org/info/IMG/pdf/Greenpepper.pdf>

29 Correlation Network; Making voices heard – study on access to health and social services for substance users, Amsterdam, 2008

30 Based on a consultation in April 2010 with Jason Farrell (Consultant)

31 Has service users participation made a difference to social care services? Position Paper No 3, SCIE, 2004

## Conclusions

Based on the determinant analysis, I could identify a number of critical factors. At the same time this allows me to answer two of my research questions:

Why is it important to guarantee involvement and participation of drug users?

Involvement and participation of service users and DU's in particular is considered one of the major future challenges, both by service providers and by policy makers. This awareness is increasingly reflected by legal regulations and frameworks. It is generally assumed that participation fits the values and ethics of social work and public health<sup>32</sup> and will improve the effectiveness and the outcome of the services provided, particularly when empowerment elements are included.<sup>33</sup> Additionally it reflects the shift from the more patronizing public health model towards a more democratic and pluralistic model, in which service users are seen as equal partners in the development of health strategies and policies<sup>34</sup>.

Which determinants are related to the lack of involvement and the participation of drug users?

The legal framework increasingly supports internal and external participation processes. Nevertheless, there is a lack of transparency, a lack of understanding and awareness, a lack of support and commitment and a lack of experience: it is generally assumed that participation increases the complexity of the decision making process, while it is often questioned whether participation has any effect on the health situation of the target group.

An important obstructing factor is the stigma on drug use. DU's are generally not seen as equal partner in the participation process but they are being patronised, which applies to both policy makers and service providers. Also DU's might need additional capacities and skills to participate effectively. There is also a lack of resources, manpower and facilities – DUO's often depend on the commitment of a few dedicated members of the group. The new generation of DU's is often not involved at all within service delivery and policy making. DUO's often need support, but there is a danger that non-DU's predominate the organisation and the movement. Last but not least, it can be assumed that many national and local DUO's face problems and feel isolated, while the DU movement on a European and international level is more visible – building on the input and the expertise of the various national DUO's.

32 Seden, Janet; Innovation still needed? Service user participation in social care services and practice led management; *The Innovation Journal*; *The Public Sector Innovation Journal* 13 (1), 2008, Article 5

33 What is the evidence on effectiveness of empowerment to improve health? WHO Regional Office for Europe's Health Evidence Network (HEN); February 2006

34 Horstman, Klasien: Mobiliseer de dikkerds, de rokers en de drinkers, *Volkskrant*, 11 juli 2010

# 3 Participation models and theories

This chapter of the paper will focus on the question which strategies and models currently exist to stimulate the involvement and participation of drug users and which limitations are inherent to these strategies.

One of the best known participation models is the participation ladder of Sherry Arnstein<sup>35</sup>, introduced in 1969 – more than 40 years ago. She ranked various forms of citizen participation, in which she distinguished a number of levels and rungs.

Arnsteins greatest merit was that she unmasked empty participation processes, most often initiated to create a justification for decision makers. Arnsteins model is strongly focusing on the term power, distinguishing two groups of people - those who have power and those who don't: the haves and the have-nots.

Manipulation and therapy are both considered to be non participative. The idea behind it is that participants need to be cured or to be educated.

Information is the first step towards participation, but it is clearly a one-way road.

Consultation – another step in the right direction, but no guarantee that anything will be done with your opinion.

Placation – Advice can be given, but the power holder retains the right to judge the feasibility or legitimacy of the advice.

Partnerships – Power is redistributed through negotiation. Planning and decision-making responsibilities are shared.

Delegated power – a majority of citizens hold seats in decision making bodies and have the power to decide.

Citizen control – former have-nots have all power (planning, policy making and managing) in hands.

Besides the fact that Arnsteins descriptive model is a strong simplification of reality, it does not address the process of participation, the needs of the various target groups, the difficulties to get people involved, how to organise participation processes and, last but not least, it doesn't make any distinction between the various purposes of participation. Arnsteins plead is that citizen participation should generally lead to citizen control. Holding the power is the final and ultimate goal, regardless if this corresponds with the ideas of the powerless.

David Wilcox [1994] developed a guide to effective participation, partly based on Arnsteins model. He altered her model into 5 stances of participation:

- ✘ Information
- ✘ Consultation
- ✘ Deciding together
- ✘ Acting together
- ✘ Supporting independent community interests

Wilcox and Arnsteins theories do not differ so much in terminology and classification. The various levels and stances of participation are more or less the same in both models. However, Wilcox links the level of participation directly to the purpose of participation, the interest of the stakeholders and the phase within the process. By doing so, he acknowledges the fact that different purposes might legitimate different levels of participation and that there is not one community, but different stakeholders with many interests. Not all 'stakeholders' are interested in full participation, which then requires a different approach. Last, but not least Wilcox distinguishes four main phases within the participation process: initiation - preparation – participation – continuation.<sup>36</sup>

Pretty et al. (1995) gives good guidance, when it comes to the purpose of participation, by identifying 7 different types of participation.

At the lowest level, the *passive participation*:

professionals have complete control of the program, the planning, the organisation of activities.

The target group is only informed about what is going to happen. Example: Drug Users in methadone treatment.

The second level is the *participation in information giving*,

in which the target group is participating by answering questions from researchers, services, policy makers, without having any influence on decision making. Example: Research settings.

When it comes to *participation by consultation*, the target group can express its views and needs. Their feedback can influence the process and the decision making, but there is no obligation to do so. Example: Policy and civil society consultation processes.

35 Arnstein, Sherry R.: A ladder of Citizen Participation, JAP, Vol 35, No 4, July1969, pp.216-224

36 Wilcox, D. ; The guide to effective participation; www.partnerships.org ; 1994

The *participation for material incentive* includes that the target group participates by providing specific resources such as labour in exchange for money or other material incentives. They can influence the work setting, but not the process and the strategies being used. Examples: Reintegration and activation projects for drug users.

*Functional Participation* means that the target group participates by contributing to predetermined objectives (mostly not from the very beginning). Control and responsibility are still in the hands of the professionals. Example: peer workers in the field of HIV/AIDS prevention.

*Interactive Participation* stands for the cooperation between the target group and the professionals, they work in partnership by using interdisciplinary methodologies. Knowledge is being shared to gain understanding and develop common actions. Example: Action Research.

The highest level of participation is being described as *Self-Mobilisation*. Professionals remain in the background or do not play any role at all. The target group makes their own choices, decisions and has complete control of the planning and implementation of activities. Example: Drug User Organisations<sup>37</sup>.

Tritter and McCallum<sup>38</sup> have critically assessed the theory of Arnstein, arguing that “by solely emphasizing power, it limits effective responses to the challenge of involving users in services and undermines the potential of the user involvement process.” This results in a one-dimensional model with a strong focus on the outcome rather than on the process of participation and involvement. Moreover, they argue that Arnstein ignores a number of aspects such as the methodology, the category of users, including their capacities to participate and the outcomes of the participation process.

Summarising the various models and critical remarks, it can be concluded that participation is more than just the redistribution of power. The process of participation is sometimes more important than the outcome. Last but not least, the purpose of participation, the interest of the various stakeholders, the category of users and the capacities of the target group should finally determine the level of participation.

Consequently, I want to plead for a more elaborated working model, taking into account the model of Wilcox and the critical remarks of Tritter and McCallum, as their approach seems to fit best to the particular situation of drug users.

37 Pretty et al. (1995): Participatory Learning and Action. A trainers' Guide; Sustainable Agriculture Programme, International Institute for Environment and Development, London, 1995

38 Tritter, Jonathan Quetzal & McCallum, Alison: The snakes and ladders of user involvement: Moving beyond Arnstein. Elsevier Ireland Ltd., 2005

# 4 Towards a more realistic approach

## the roadmap for effective participation

This chapter links relevant determinants and aspects of the participation process - which have been assessed during the context analysis - with the model of Wilcox and Pretty et al. and the critical remarks of Tritter and McCallum. In addition a number of core elements are identified, which will allow a more realistic approach, taking into account the specific situation of DU's. These elements focus on the process of participation, including the different phases within the participation process, the interest of the various stakeholders, the level of influence, the methods used and the resources.

The process of the participation takes time and has at least 4 phases, in which various issues need to be tackled. A leading principle should be that DU's are involved in the development and design of the process from the very beginning.

During the initiation phase the cooperation and the inclusion of DU's start. The purpose of the participation process needs to be defined and a relevant number of DU's need to be selected for the further preparation of the participation process.

The preparation phase is the most important phase within the process, resulting in a working plan, consensus paper or roadmap, which helps to organise the process properly. This document clearly describes the purpose of the participation process, the methods to be used, the selection process of the various participants, the mandate and level of influence of the group, the expected results, the timeline, the resources available, the support needed and an estimation on how much time, energy and money this process will cost. Accordingly, a common strategy is developed – a roadmap for successful participation, including preparatory elements, such as training and skill building. Finally a definite working group, expert group or consultation group is being formed, including a relevant number of DU's who are willing to dedicate time to the process.

During the implementation phase of the participation process the strategy or roadmap is being implemented.

The final phase of continuation includes the evaluation and the adaptation of the strategy with a main focus on the results and the level of satisfaction among all participants in the process.

Distinguishing the various phases in the participation process helps to organise and structure the final implementation. The development of a decent strategy or roadmap, including the various steps, will contribute to an effective implementation and transparency in the process.

A large number of aspects need to be discussed and agreed upon during the initiation and preparation phase. The implementation phase is being used to roll out the activities, according to the roadmap, while the last phase is being used to evaluate and adapt the plan for the continuation of the activities.

The development of a decent roadmap for participation requires time and the willingness to discuss a number of key questions.

First of all the preparation group needs to agree on the purpose of the participation process. Is it about policy making on national or international level, is it about decision making within an organisation (e.g. client council) or is it about the more practical issues in regard to service delivery (e.g. peer education). Which results are expected at the very end? Is the same point of view shared by all stakeholders in the process? Being transparent about the purpose of the participation is important as it will determine to a great extent the way the participation process is being organized. The model of Pretty et al. (1995) can guide the various partners through this part of the process.

As a next step it is important to discuss the role and the interests of the various stakeholders and to check whether the expectations of the different partners sufficiently match with each other.

Another relevant aspect is the level of influence and power. What are the mandate and the status of the consultation group and the individual DU's, involved in the process? What can the group decide about? Is it about consultation, advising or about making decisions?

One question, which is often neglected at the very beginning, is whether the various stakeholders need training, skill building or supervision. Training and support builds capacities and contributes to an effective and equal participation process. This does not only apply to DU's, but also to service providers and policy makers. After all, they are mostly inexperienced when it comes to consultation and cooperation with DU's. If additional support is needed, it is important to reserve sufficient financial resources for this part.

The roadmap should also include the methodology being used in the participation process. How is participation being ensured? Do the methods fit the purpose of the participation process and the capacities of the participants?

Last but not least, it is essential to be transparent about the resources, which are available. This should include fees (also for the DU's being involved), capacity building, travel costs and participation at conferences. Sufficient resources might also reduce the pressure on individual DU's and may stimulate the participation of additional DU's. Peer involvement is often promoted as cost effective – which it is – but this should not be confused with the idea that it is a cheap solution. Not investing in DU's and DU involvement is also a kind of disrespect.

The elements mentioned in this step-to step approach may give an idea and some kind of guidance when it comes to participation processes. I have tried to identify the various critical factors, which are inherent to the involvement of DU's. However, taking into account the great variety of realities, restrictions and (financial) limitations in Europe we must assume that this assessment can only give a very general overview of influencing determinants. Nevertheless, this roadmap can be used as a supporting guidance document when it comes to participation of DU's.

# ROADMAP FOR SUCCESSFUL IMPLEMENTATION OF PARTICIPATION PROCESSES

Phase	Process			Result
<b>I.</b> INITIATION PHASE	Why do we want to cooperate with DU's?	Who can we invite to think with us?		Preparation Group
<b>II.</b> PREPARATION PHASE	Why are we here? What is the purpose of this process?	Is this purpose acceptable for all partners? (agreement and consensus)	What do we want to achieve? What should be the results and until when should they be achieved? (agreement and consensus)	Roadmap
	How can we achieve these results? (agreement and consensus)	Whom do we need for this? (Final working group, including a relevant number of DU' s)	What do we need for this? (e.g. financial resources, manpower, time investment, training, skill building)	Formation Working Group
	Can we realise this? If not, can we still agree on continuatio	What is the role of the various partners? What is their mandate, their status and their level of influence? (agreement and consensus)	What are we going to do and when?	
<b>III.</b> IMPLEMENTATION	MONITORING			Participation Process
<b>IV.</b> EVALUATION	Where are we now? Did we proceed as we planned to do?	What are the results? Did we achieve what we intended to achieve?	What were the drawbacks and successes in the process?	
	What needs to be changed in the future process to ensure successful continuation of the process	What is the overall satisfaction of the partners?	How did the various partners experience their participation and role?	Continuation of the process

# 5 Conclusions

This paper analyses factors and determinants which facilitate or jeopardize the process of participation, by reviewing literature, but also by strongly referring to the experiences in the field. These factors are linked with a number of existing models and ideas in order to develop a more practical approach for the participation of DU's.

Participation and involvement is a broad and diverse issue and most importantly a process which makes it difficult to develop a universal and prescriptive model. There are numerous purposes for participation, which determine the way to organise the process accordingly. The involvement on policy level requires a totally different approach than the participation of DU's on service provision level. Nevertheless, there are a number of common key elements which make participation processes work. One of the most important prerequisites is the serious intention and willingness to organise participation in a respectful and decent way. Keywords are: integrity, transparency and equality, as well as planning, resources, time, energy and patience.

On the other hand there are numerous drawbacks on political, organisational, as well as individual level. The stigma attached to drug use is an important element, which creates major barriers to the participation of drug users. Labelling drug users as deviant, as criminal, as sick person or as someone, who cannot take care of himself, turns participation of DU's per definition into a farce.

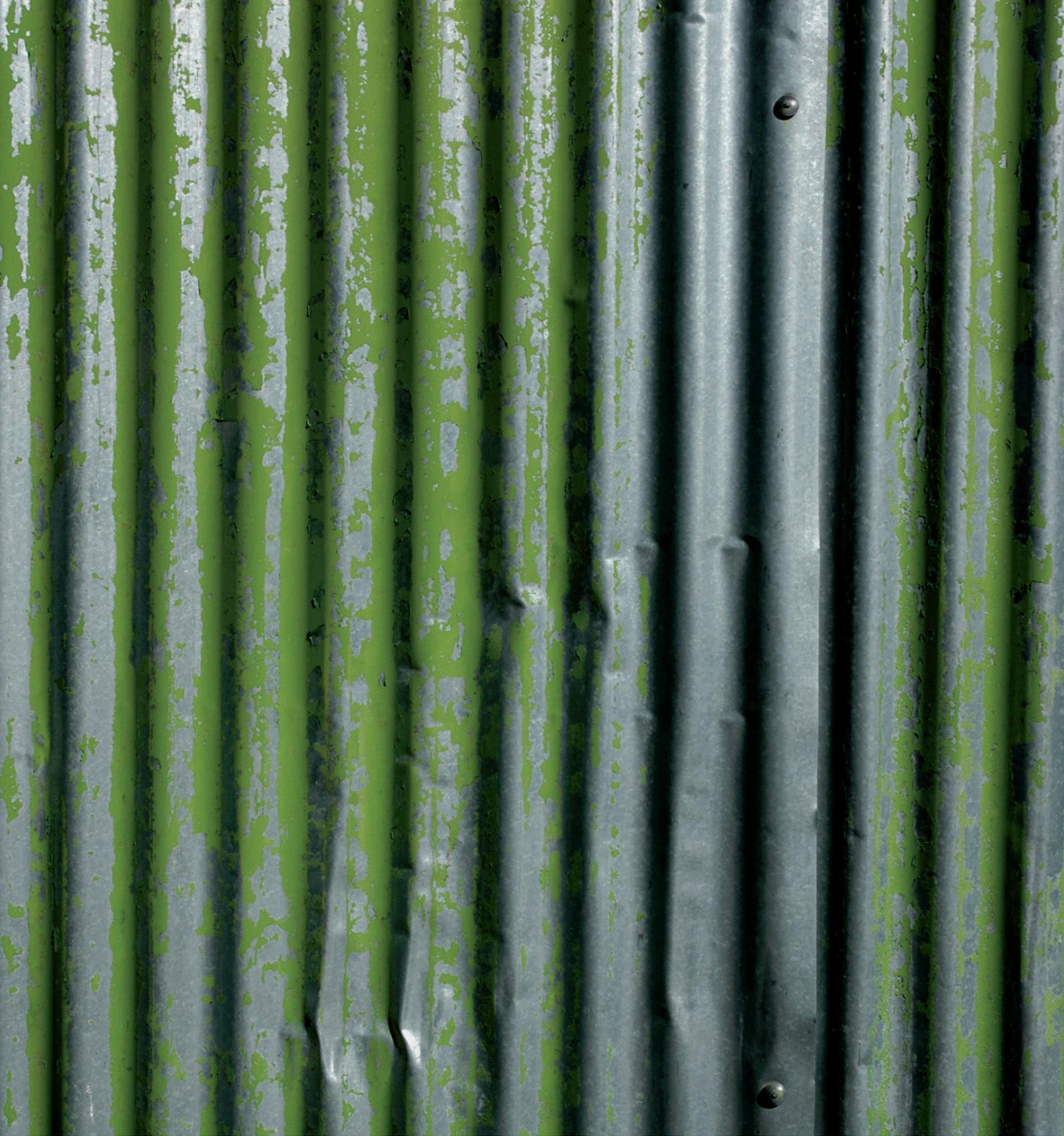
The paradigm shift within the public health from the patronizing model towards a more democratic and pluralistic approach makes it essential to organise participation in a meaningful way. It is essential for all parties involved to plan the process carefully. The preparation phase is the most extensive one and there should be a realistic timeline, taking into account the various issues. Additionally, it needs to be checked whether skill building or training is necessary, if there are sufficient resources.

Most often participation is an open process, initiated with the idea to be continued in the future. With this idea in mind it becomes easier to start experimenting. Most important is that participation and involvement of DU's is organised in a respectful way, with the intention to really move things forward and cooperate with DU's in a respectful way. Although the roadmap does not pretend to be perfect and complete, it can support service providers, policy makers and DU's in organising participation more effectively.



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**Correlation**  
European  
Harm Reduction  
Network