European Commission

Training packages for health professionals to improve access and quality of health services for migrants and ethnic minorities, including the Roma

MODULE 4: KNOWLEDGE APPLICATION

Unit 5: Community-based approaches, promotion of user and community participation and involvement

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Outline of the session

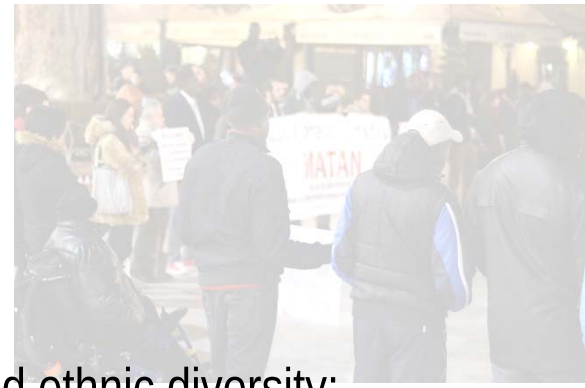
- Activity 1 The Own Community
- Presentation Part I: Introduction
- Activity 2: Perceptions and Stereotypes
- Presentation Part II: The Fundamentals and Definitions of Community-Based Approaches
- Activity 3: Levels of Involvement and Participation
- Presentation Part III:
  - ✓ Concepts and Relevant Aspects related to “Involvement” and “Participation”
  - ✓ Challenges, Limitations and Strategies Related to Community-Based Approaches
- Activity 4: Power / Control Relationships and Relativity

Activity 1
The Own Community

- In pairs
  - ✓ One person tells the other about the own community, including the following questions:
    - Do communities exist?
    - What does the idea of community evoke?
    - Do you feel belonging to a community?
    - Who / what constitutes your own community?
    - Do you / your health care users belong to a community?
  - ✓ Role change.

- In the plenary
  - ✓ Each person from a pair presents the other person's perceived community.

Introduction



- Approach to health care services oriented towards cultural and ethnic diversity:
  - ✓ Based on inclusion and multi-dimensionality.
  - ✓ Focused on the reduction of inequalities in health in the context of a community.
  - ✓ Multi-sectorality.
  - ✓ Inclusion of the needs of migrants and ethnic minorities, including the Roma, throughout the entire health design and delivery process.

- Importance of moving towards a migrant / ethnic minorities-inclusive health system rather than parallel specific groups-responsive services outside the mainstream.

Activity 2:
Perceptions and Stereotypes

- In the plenary:
  - ✓ Look at the photos.
  - ✓ Which words come to your mind when describing a group / a community of migrants and ethnic minorities, including the Roma?
  - ✓ Write down the words on post-its and stick them to the wall, next to the photos.
  - ✓ Discussion.

Activity 2: Perceptions and Stereotypes









Pictures: Andalusian Childhood Observatory (OIA, Observatorio de la Infancia de Andalucía) 2014; Josefa Marín Vega 2014; Morguefile 2014.

Fundamentals
of Community-Based Approaches

- Not so much about epidemiological profiles, rather about socio-economic aspects, cultural understanding and respect, diversity and linguistic appropriateness.

- Innovative services
  - ✓ Interpretation and translation.
  - ✓ Culturally and ethnically informed health care and programmes.
  - ✓ Use of community support (intercultural mediators, community health workers, patient navigators).

- Project examples
  - ✓ Health Mediation Programmes
  - ✓ HIV/STI Prevention Projects
  - ✓ Reproductive Health and Harm Reduction Projects
  - ✓ Mobile Services

Roma Health Mediators Programme

- Language and cultural barriers → negative effect on access to care and prevention services, adherence to treatment plans, timely follow-up, and appropriate use of emergency departments.

- Roma health mediators
  - ✓Wide range of roles (interpreter, patient advocate, health educator).
  - ✓Added bonus of facilitating social integration for both the services and those they serve.

Video: Roma Health Mediation in Europe, IOM, International Organization for Migration, 2014:
https://www.youtube.com/watch?v=EarpvGr6n5k

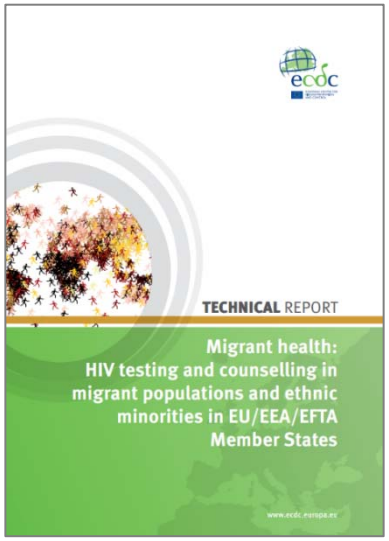
Evaluation of a Health Mediation Programme

- Evaluation of a Health Mediation Programme

- Success factors:
  - ✓Institutionalization of the programme.
  - ✓Involvement of local communities.
  - ✓Focus on preventive health care.
  - ✓Adapted messaging.
  - ✓Unintended consequences of positive gender roles.
  - ✓Female employment.
  - ✓Improved daily living conditions

- Cost-effectiveness:
  - ✓Improved access to existing services.
  - ✓More frequent and adequate use of existing health services.
  - ✓Better adherence to treatment.
  - ✓Significant increase in vaccination rates.
  - ✓Improvement in the use of contraception methods.

HIV / STI Community Prevention Programme:
Naz Project



- ECDC Case Study “The Naz Project”
  - ✓ In partnership with the Chelsea and Westminster Hospital in London.
  - ✓ HIV and other STIs testing service for black and minority ethnic groups.
  - ✓ Translation service, pre- and post-test information.
  - ✓ Appointments by outreach community workers.
  - ✓ Weekly clinic in the afternoon.
  - ✓ In case of positive testing: Confirmatory testing and clinical follow-up.
  - ✓ Main challenge: Insurance regulation.

Community Projects:
Harm Reduction Approaches and Mobile Services

- **Harm reduction approach**
  - ✓ Harm reduction programme for drug users and sex workers.
  - ✓ HIV/STI prevention, diagnosis and treatment, socio-economic reintegration, protection of Human Rights, vaccination, mental health services.

Video: Médicins du Monde, La Réduction des Risques, 2011.
https://www.youtube.com/watch?v=J-HJ_LVnWs0&authuser=0

- **Mobile clinics / Health units**
  - ✓ Health care services addressed to Roma population in Bordeaux.

Video: Médicins du Monde, Mission Rroms Bordeaux, 2011.
https://www.youtube.com/watch?v=GEr70CklM3s

Médicins du Monde 2011a, 2011b.

Community Projects:
Health Prevention and Reduction of Health Disparities

- Intercultural community health prevention
  - ✓ MiMi, Mit Migranten für Migranten, Ethno-Medizinisches Zentrum e.V.
  - ✓Activities: Training in health mediation, information activities.
  - ✓Objectives: Health prevention, integration of migrants and reduction of health disparities.

- Training activities
  - ✓Pharos, Expertisecentrum Gezondheidsverschillen
  - ✓Activities: Training, conferences, patient panels, school programmes, support activities.
  - ✓Objectives: Reducing health disparities and improving quality, effectiveness and accessibility of health care for people with limited health literacy and migrants, reinforcing prevention and self-management.

Ethno-Medizinisches Zentrum e.V. 2009; Pharos 2015.

Community Development

The term community development has come into international usage to connote the processes by which the efforts of the people themselves are united with those of governmental authorities to improve the economic, social, and cultural conditions of communities, to integrate these communities into the life of the nation, and to enable them to contribute fully to national progress.

This complex of processes is, therefore, made up of two essential elements:
- the participation by the people themselves in efforts to improve their level of living, with as much reliance as possible on their own initiative; and
- the provision of technical and other services in ways which encourage initiative, self-help and mutual help and make these more effective.
(UN 1956, in UNESCO 1956: 9).

UN 1956, in UNESCO 1956.

Definition
of a Community-Based Approach

- Relevance of working definitions.
- Complex, time-sensitive and theory-bound character of the definitions.

Working definitions:

- Community refers to a population whose members share some common interests, needs, demands, geographic areas, traits, values, cultures, and possibly religions.
- Community-based approach or action aimed at improving access and quality of health services for populations of migrant and ethnic minorities' would refer to collective but local efforts by those communities which are directed towards increasing community control over the (local) determinants of health.

Community-Based Approaches:
Bottom-Up Approaches

- Bottom-up approach
  - ✓ Start: Population (demands, stakes and uncertainty, situations and interests).
  - ✓ Up: Drafting proposals and participatory situation study.
  - ✓ Up: Objectives and activities negotiated by the population with the partners.
  - ✓ Up: Dynamics (local social development, health promotion, health education).

- Relevance of health literacy.

- Use of digital tools.

Community-Based Approaches:
Relevant Aspects

- Characteristics of community-based approaches
  - ✓ Based on open, two-way dialogue, intersectorality and participation.

- Complexity of working with communities.
  - ✓ Participation of a person in collective action: gradual construction, through awareness of belonging to a group.

- Contribution of mediation
  - ✓ For communities and their members: To learn from mediators how to integrate healthier lifestyles in their routines, how to access health care and utilize it.
  - ✓ For health professionals and policy makers: To learn from mediators how to lower the threshold to facilitate access to services.

Concepts
of “Involvement” and “Participation”

Primary health care: (…)
5. requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate;
(WHO 1978: 2)

[T]he population’s involvement helps not only to improve the quality of programmes, by providing a more precise analysis of the situation and context, but also recognises the right of these populations to self-determination. Participatory actions are therefore part of defending patients’ rights and access for all to social rights.
(Médicins du Monde 2012: 5)

Médicins du Monde 2012; WHO 1978.

Ladder of Community Participation

- Ladder of Community Participation: Arnstein 1969.
- Different levels: Non-participation – Tokenism – Citizen Power.

Participation in health policies decision making

Participation in project design, development and assessment

Participatory Action Research, participation in health related projects

Surveys on health related issues; participation forums; research projects

Health promotion and prevention campaigns; information on legal changes

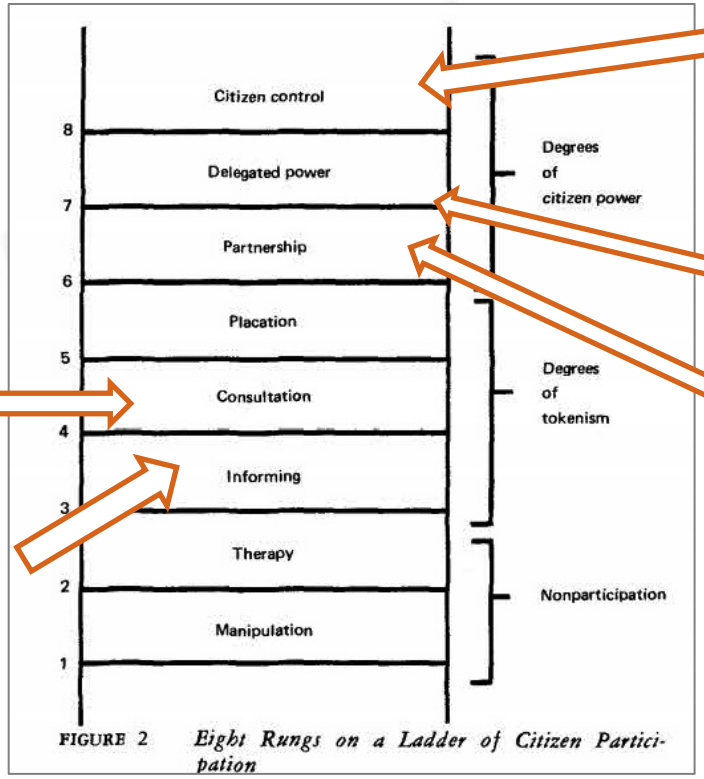


FIGURE 2 *Eight Rungs on a Ladder of Citizen Participation*

Arnstein 1969.

Levels of Involvement and Participation

Full control: Service users control decision making by community-run committees or groups.

Sharing power: Shared decisions and responsibility, incl. governance level. Service users have influence by 'tailored' staff recruitment or supported volunteering.

Participation: Encouraging people to take part in shaping services, policies or perceptions. Service users have influence by suggestions, focus groups, participatory appraisal, stakeholder events, peer research or education.

Consultation: Asking people what they think of a service or policy. Service users have limited influence by questionnaires, interviews, focus groups or suggestion boxes.

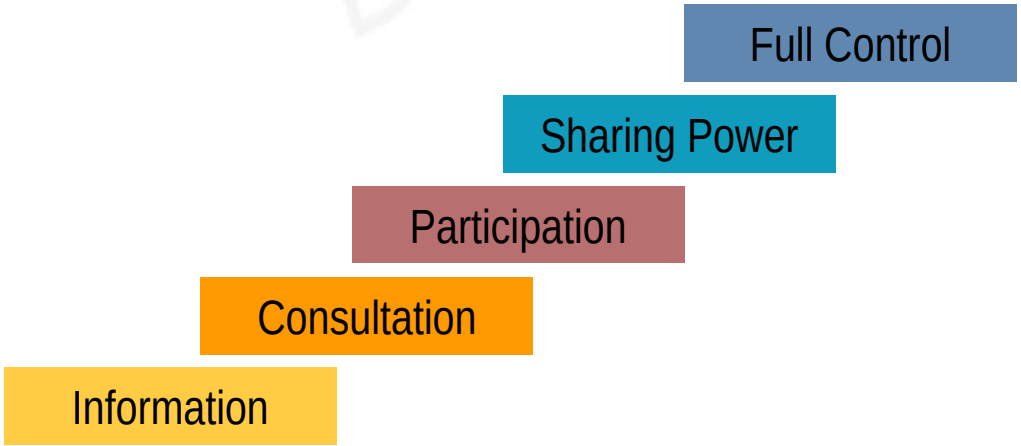
Information: Telling people about a service or policy, by means of newsletters, leaflets, notice boards or digital information. Service users have no influence.

FEANTSA 2013; figure: own elaboration.

Activity 3:
Levels of Involvement and Participation

- In small groups:
  - ✓ Which level of involvement and participation exists in your professional context for migrants and ethnic minorities?
  - ✓ Which strategies can you identify to increase the level of involvement and participation?

- In the plenary: Summary and discussion



FEANTSA 2013; figure: own elaboration.

Relevant Aspects
related to Involvement and Participation

- Deliberate, systematic inclusion of individuals, families and communities as active players in the improvement of their own health and the services they use.

- Trust, a sense of belonging and mutual respect in order to understand and manage the expectations and goals of the various parties.

- Progressive empowerment model, engagement in different aspects of health service management.

- Role of community representatives: Bridging the gap between communities and health services, participating as interpreters, mediators and educators, as well as contributing professional knowledge.

- "Participation" and "involvement": Often used interchangeably, different levels and forms.

Relevant Aspects
related to Involvement and Participation

- Consider time availability
- Consider proximity
- Consider hetero- vs homogeneity of the groups
- Consider power relationships
- Take into account local initiatives and collective dynamics

Challenges and Limitations
of Community-Based Approaches

- Challenge of efficiency / effectiveness at the local level.
- Challenge of proximity, simplicity and time.
- Challenge of socio-cultural adaptation and involvement.
- Challenge of apprehension and comprehension of needs.
- Challenge of ethical aspects and lack of acceptance.
- Challenge of reconciling different types of knowledge.

Ethno Medizinisches Zentrum 2015; Médicins du Monde 2013.

Strategies
for Community-Based Approaches

- What to avoid?
  - ✓ Tokenism and ‘apparent’ participation.
  - ✓ Consultation fatigue.
  - ✓ Lack of appreciation.
  - ✓ Creating fears.
  - ✓ Reinforcing stigmatization.

- How to promote changes in the community?
  - ✓ Encourage the community to choose an approach that is consistent with its values.
  - ✓ External interventions impose changes on the community value system.
  - ✓ Values can change, but this change cannot be accelerated or imposed.

Benefits
of User and Community Involvement and Participation

- For the person involved:
  - ✓ Personal gain or empowerment from being involved, increased confidence, knowledge, skills or awareness.
  - ✓ Long-term gains from improved policy or practice.

- For the communities:
  - ✓ Raising awareness.
  - ✓ Improving perceptions of migrants and ethnic minorities, including the Roma, correcting images and dispelling myths and stereotypes.
  - ✓ Long-term gains from improved policy or practice.

Benefits
of User and Community Involvement and Participation

- For the organization:
  - ✓ Better adjustment of practices to needs and aspirations of service users.

- For planners and policy-makers:
  - ✓ In case of politically timely or relevant outcomes of participation.
  - ✓ Risk of time lapses between participation and result change at policy level.
  - ✓ Results often not tangible in the short term.

Activity 4:
Part I: Power / Control Relationships and Relativity

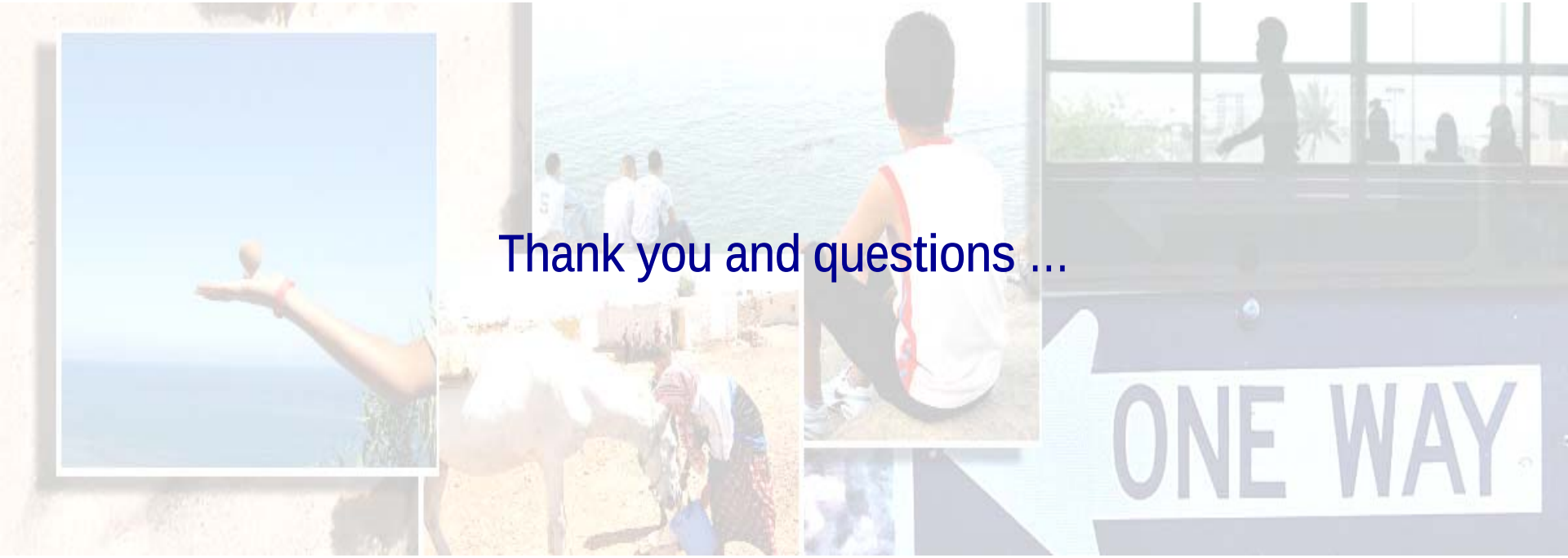
- In the plenary.

- Activity: Power / Control Relationships and Relativity (Part I)
  - ✓ Each person in the group draws a number from a secrete name box (1-10, 1: the least power, 10: the most power).
  - ✓ Without revealing their number, each person has to walk around in the room together with outer participants, representing a role of the imagined ‘degree of power’.
  - ✓ Each person has to observe others in order to identify in the end the number they were supposed to be playing.

Activity 4:
Part II: Power / Control Relationships and Relativity

- Activity ”Power / Control Relationships and Relativity” (Part II)
  - ✓ Each person in the group draws a character from a secrete name box.
  - ✓ Each character has to place him/herself in relation to a ‘point of power’ identified in the center of the room, as well as to other characters according to the perceived control they hold in terms of 1. their own health, 2. the health of the health care users, 3. the health of other people in the local community.

- Exchange of experiences and discussion.



Thank you and questions ...

Pictures: Andalusian Childhood Observatory (OIA, Observatorio de la Infancia de Andalucía) 2014; Josefa Marín Vega 2014; RedIsir 2014; Morguefile 2014.

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