SESSION 4: Community Participatory Research and Policy-Making: Initiatives with Different Set-Ups

Hilde Geurts, Monique Post
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Course Materials
The purpose of these materials is to help provide an introduction to the Summer Institute session on stakeholder participation at the systems level. The materials were designed to prepare trainees who are unfamiliar with stakeholder participation with the general background to get the most educational benefit from the session. Toward this objective, we have prepared the following: (1) learning objectives for this session; (2) some key terms and concepts to become familiar with participatory research; and (3) some recommended resources. These materials could be considered “prerequisites” in preparing for this session.

In collaboration with the presenters, these materials were developed by Marie Deserne from the University of Amsterdam (M.K.Deserno@uva.nl) and Michelle Hoogenhout from the University of Cape Town (michelle.hoogenhout@uct.ac.za). Feel free to contact us with questions/comments.

Register for this course and other sessions in this series at https://www.autism-insar.org/events/EventDetails.aspx?alias=SI2018
Learning Objectives
The INSAR Summer Institute for Autism Research was established to provide early career researchers (graduate students, postdocs, etc.) with training opportunities in multidisciplinary topics. The Summer Institute team is now working to engage stakeholders as well. Summer Institute priorities are to provide a (1) freely available (2) multidisciplinary training platform for young scientists and others from various backgrounds that (3) allows for international participation. The Summer Institute covers broad topics and is meant for people who are not expert in the topic area. It is offered over a free web platform and allows researchers and stakeholders from around the world to connect with the presenter(s). The overarching goal of the Summer Institute is to expose junior scientists and community members to topics they are not currently engaged in, with the hope that basic scientists, clinical scientists, and the autistic community can learn from each other and advance the understanding of autism.

The current session is led by Professor Hilde Geurts and Monique Post.

The learning objectives for attendees of this session include:

• Knowing which collaborative efforts are undertaken in the Netherlands.
• Learning what does and does not work in such collaborations.

Key Terms

Academic working consortium
In the Netherlands, there are two Academic working consortia for autism, REACH-AUT (www.reach-aut.nl) and Joint Effort! (www.autisme-samendoen.nl). Within these consortia, people with autism, their families, carers, policymakers and researchers collaborate in several project groups. The working consortia operate jointly to make sure their outputs complement each other.

REACH-AUT projects:
1. Lifetime: what are the important risk and success factors throughout the lifetime?
2. Care network: is a better quality-of-life possible with better organised care?
3. From genetic laboratory to patient: knowledge sharing and joint decisions.
4. Transitions in education: more knowledge & better handling.
5. Successful development of independence within multiplex families: contributory factors.
7. Phases of transition: autism and the elderly. What can we do for them now?

Joint Effort! projects:
1. Early detection
2. Early treatment
3. Preparing teachers
4. Educational transitions
5. Relationships
6. Access to employment
7. Care transitions
8. Housing
Autism Europe
Autism Europe is an international association whose main objective is to advance the rights of autistic individuals and their families and to help them improve their quality of life.
(www.autismeurope.org)

Dutch Health Council
The Dutch Health Council, de Gezondheidsraad, is an independent scientific advisory body for government and parliament in the Netherlands.

Feedback panel
Each project embedded in the Academic working consortia discusses their study design, progress and results with their project-specific feedback panel. These panels consist of autistic individuals, care providers and family members of autistic people.

Ministry of Health, Welfare and Sport (VWS)
VWS is an abbreviation used for the Dutch Ministry of Health, Welfare and Sport.

Nederlandse Vereniging voor Autisme (NVA)
NVA is a Dutch advocacy association for autistic individuals.
(www.autisme.nl)

Personen uit het Autisme Spectrum (PAS)
PAS is a Dutch advocacy association run by and for autistic individuals.
(www.pasnederland.nl)

Vanuit Autisme bekeken (VAB)
VAB is an initiative that contributes to making the Netherlands a more inclusive society for autistic individuals.
(www.vanuitautismebekeken.nl)

ZonMw
In the Netherlands, ZonMw is an independent self-governing national funding organisation with a central role in health care research and practice. Next to funding from mental health clinics, ZonMW has partly funded the two Academic working consortia, REACH-AUT and Joint Effort!

Recommended Readings & Resources