SAPIENZA
Università di Roma

NEUROPECULIAR
Movimento per la Biodiversità Neurologica

GRUPPOASPERGERLAZIO
ODV

CNR
ISTC
ISTITUTO DI SCIENZE E TECNOLOGIE
DELLA COGNIZIONE

WORKSHOP
AUTISM and PARTICIPATORY RESEARCH

8 - 9 March 2024 ONLINE

In **participatory research**, **autistic people and/or their caregivers** take an active part in the research process as lived experts in autism. In participatory research studies, the autistic community can play **different roles** characterised by different levels of power compared to the researchers (autistic and non-autistic).

This workshop aims to **raise awareness of participatory research and promote it among research groups and the Italian autistic community**, thanks to the contributions of researchers and autistic people who have had direct experience of it. The event offers an opportunity for training and discussion around a topic that bridges **psychology**, **ethics** and the **social sciences**.

Organisers

This workshop is part of the Third Mission project 'Listening to the Autistic Community' sponsored by the Faculty of Medicine and Psychology, Sapienza University of Rome, in collaboration with the Autism and Participatory Research Working Group, Neuropeculiar aps, Gruppo Asperger Lazio odv and ISTC-CNR.

Who is this workshop aimed at?
- Researchers conducting research in the field of autism
- Autistic people
- Caregivers of autistic people
- Professionals who work with autistic people in social/health/educational/caregiving settings
- People interested in autistic friendly research and participatory research

Where and when will the workshop be held?
The workshop will be held online, via Zoom.
Registered people will receive the Zoom link by the morning of the event.

The workshop will be held over two days:

- **Friday, March 8** - from **2:15 p.m. to 7 p.m**
- **Saturday, March 9** - from **9:30 a.m. to 1:30 p.m**

How to participate in the workshop?
Participation to the workshop is **free of charge**.

To **register**, you must **fill out the following online form**:
https://forms.gle/HZm1RxQE55dEYfdt9

Language
International speakers will speak in English, and a brief summary in Italian will be made available in the chat.
Italian presentations will be summarised in English in the chat.

Contact
For any questions regarding the event you can contact us at the following address:

beatrice.baldi@uniroma1.it

PROGRAMME

Friday March 8th 2024
from 2:15 to 7:00pm

2:20 - 2:30 pm
Opening message and guidelines for the webinar

2:30 - 2:40 pm
The italian autism participatory research working group
Giovanni Granato (autistic, ISTC-CNR, Italy)
duration: 10 min

2:40 - 3:50 pm
KEYNOTE: Autism participatory research: what is it and why are we doing it?
Liz Pellicano (non-autistic, University College London, UK)
duration: 50 min + 20 min Q&A

Break (10 min)

4:00 - 5:10 pm
KEYNOTE: How is autism participatory research done?
Christina Nicolaidis (non-autistic, AASPIRE Portland State University, USA)
duration: 50 min + 20 min Q&A

Break (10 min)

5:20 - 6:50 pm
Experiences of autism participatory research studies
Panellists will share their experiences of conducting / being involved in autism
participatory research.

Alice Scavarda (non-autistic, University of Turin, Italy)
Martina Fusaro (non-autistic, Sapienza University of Rome, Italy)
*Isabelle Flahaux (*autistic, LAVA, Belgium)
Ilse Noens (non-autistic, University of Leuven, Belgium)
Silke Lipinski (autistic, Autism Research Collaboration, Humboldt-Universität zu
Berlin, Germany)
Lorna Hamilton (non-autistic, York St John University, UK)
Kathryn Lewis (autistic, York St John University, UK)
Ariel Schwartz (non-autistic, University of New Hampshire, USA)
duration: 90 min

6:50 - 7 pm
Final greetings and invitation to Saturday

Saturday March 9th 2024
from 9:30 to 13:30

9:30 - 10:30 am
Autism and Ethics
Alice Sodi (autistic, Neuropeculiar APS, Italy)
duration: 45 min + 15 min Q&A

Break (10 min)

10:40 am - 12:00 pm
Autistic friendly research
Panel of autistic individuals, caregivers and autism researchers
sharing their positive and negative experiences of autism research

Thalia Taioli (autistic transgender woman, I FormidAbili il Blog, Italy)
Adina Adami (non-autistic, Gruppo Asperger Lazio odv, Italy)
Chiara Reali (autistic, Italy)
Liliana Ruta (non-autistic, IRIB-CNR, Italy)
Paola Binda (non-autistic, University of Pisa, Italy)

Guidelines for autistic friendly research
Ilaria Minio Paluello (non-autistic, ISTC-CNR, Italy)

duration: 60 min + 20 min Q&A

Break (10 min)

12:10 - 13:20 pm
Terminology, priorities, practices: possible conflicts between autistic people and research communities

Heta Pukki (autistic, EUCAP, GATFAR, Finland)
Eleonora Marocchini (autistic, IGDORE, Italy)
Pietro Cirrincione (person on the autistic spectrum, Autism Europe, Gruppo Asperger

onlus, Italy)
Monique Botha (autistic, University of Stirling, UK)
duration: 70 min

1:20 - 1:30 pm
Closing remarks

KEYNOTE SPEAKERS

Christina Nicolaidis

Christina Nicolaidis practices and teaches hospital-based internal medicine at Oregon Health and Science University and serves as a Professor in the School of Social Work at Portland State University. Most of her research uses participatory approaches to improve the health and healthcare of marginalized populations.
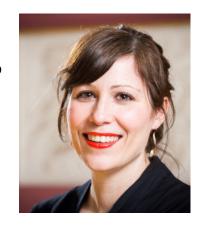
She is the co-founder and co-director of the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), an international academic-community partnership that uses community based participatory research to address the priorities of autistic adults. She has led a series of National Institute of Health (NIH)-funded AASPIRE studies on healthcare for autistic adults and has created the AASPIRE Healthcare Toolkit for use in primary care settings. She is currently leading a large NIH-funded AASPIRE R01 project to develop the AutPROM Toolbox, a set of patient-reported outcome measures to evaluate services for autistic adults.

Liz Pellicano

Liz Pellicano is a developmental cognitive scientist and educational psychologist, who has long been committed to transforming autism science so that it more accurately reflects everyday autistic life.

She is a Professor of Autism Research at University College London, having recently been Professor at Macquarie University, Sydney, Australia. Previously, she was Professor of Autism Education and Director of the Centre for Research in Autism and Education (CRAE) at UCL Institute of Education. Her most recent research, funded by a Future Fellowship from the Australian Research Council, identifies ways to bridge the gap between lab and life and open up research to greater involvement of Autistic people themselves, with the aim of generating scientific discoveries that bring real benefits to Autistic people and their families.

Other Speakers

Adina Adami (Gruppo Asperger Lazio odv)

Alice Scavarda (University of Turin)

Alice Sodi (Neuropeculiar APS)

Ariel Schwartz (University of New Hampshire)

Chiara Reali

Eleonora Marocchini (Institute for Globally Distributed Open Research and Education - IGDORE)

Giovanni Granato (ISTC-CNR)

Heta Pukki (EUCAP, GATFAR)

Ilaria Minio Paluello (ISTC-CNR)

Ilse Noens (University of Leuven)

Isabelle Flahaux (LAVA, Belgium)

Kathryn Lewis (York St John University)

Liliana Ruta (IRIB-CNR)

Lorna Hamilton (York St John University)

Martina Fusaro (Sapienza University of Rome)

Monique Botha (University of Stirling)

Pietro Cirrincione (Autism Europe, Gruppo Asperger onlus)

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