



# Announcing the EUCAP 2021 survey

the first pan-European autistic-led survey of the views and priorities of autistic people

The European Council of Autistic People (EUCAP) is pleased to announce the launch of our new survey, *Autistic Priorities*. As we are keen to maximise uptake of the survey across Europe, we welcome assistance with dissemination from all organisations and individuals who are either involved in autism advocacy or work in the fields of autism services and research.

## What is the EUCAP 2021 survey?

The EUCAP 2021 survey is a pan-European web-based survey of the views and priorities of autistic people, created by researchers who are autistic themselves. It is entirely autistic-led.

The survey seeks to map the views of autistic people in Europe on three broad issues:

- What kind of research should be conducted on autism?
- What are the needs and wishes of autistic people regarding support, care, and treatments?
- Who should advocate for autistic people in decision-making and public discourse?

## Why do we need a new autism survey?

Research on autism is too often done on or to autistic people, rather than being designed and conducted by them, with their wishes in mind. We seek to centre the autistic perspective, focusing on the views of autistic people themselves. At all stages of design, we have sought to formulate our questions in a way which is sensitive to autistic preferences, and allows them to give meaningful and relevant responses.

## How can people take part in the survey?

The EUCAP 2021 survey opens on 17th September 2021 at 9:00 am Central European Summer Time (CEST). It will be available via the EUCAP website until midnight CEST on 15th November.

The link is <https://eucap.eu/eucap-2021-survey/>

The survey can be completed by any autistic person aged 18 or older who lives in a European country. This includes both people who have been formally diagnosed and those who self-identify as autistic. Participants can choose between eleven languages in which to complete the survey. The survey is easily accessible on laptop, phone or tablet, and takes around 10-15 minutes to complete.

## How will my data be protected?

At EUCAP we are sensitive to concerns raised about potential misuse of data collected from autistic people. Survey data will be collected anonymously. The data will initially be available only to the three EUCAP researchers conducting the survey (details below).

The survey is not associated with any external research organisations, and receives no funding, being based on the voluntary efforts of autistic people who aim to promote their own human rights and those of others on the spectrum.

External researchers may request access to the data from the EUCAP Executive Board. Permission can be granted only by the Board, which consists entirely of elected representatives of autistic-led organisations.

### **How will the results of the EUCAP 2021 survey be used?**

The information gained from the survey will be published to inform the general public and raise awareness. It will be used by EUCAP and its member organisations to influence the development of autism policies and to draw the attention of decision-makers, researchers, funding institutions and other relevant bodies to autistic peoples' priorities.

We seek to build a new understanding of the views of autistic people across Europe. We hope to improve the foundation for European autistic advocacy and prepare the ground for greater integration amongst European autistic-led organisations.

### **The team behind the survey**

#### ***Silke Lipinski (Germany)***



Silke is a German researcher who is currently studying for a PhD in Psychology at Humboldt University in Berlin. Her main interests lie in the study of how to make research on autistic people more accommodating of their needs and on the study of preferences of autistic people in accessing psychological care.

#### ***Annikka Suoninen (Finland)***



Annikka is a Finnish researcher who has thirty years' experience in conducting research in the social sciences. She has contributed to a wide variety of national and international research projects related to young people and civic participation. Annikka holds a PhD from the University of Jyväskylä.

#### ***Diederik Weve (the Netherlands)***



Diederik is a co-researcher in the Dutch project Onderzoeksagenda Autisme, which works to identify needs and priorities for autism research. He is project lead of the Autminds foundation, and organises the annual autistic-led conference Autminds in the Netherlands. Until retirement, Diederik worked as a technical safety engineer in the petrochemical industry.

### **Contact details:**

For further information about the survey please contact [survey@eucap.eu](mailto:survey@eucap.eu)

For information about EUCAP see our website at <https://eucap.eu> - queries can be sent to [info@eucap.eu](mailto:info@eucap.eu)