

INNOVATING BY CONNECTING

Collaborating with the autistic community in research on support for autistic individuals



Within the Academic Collaborative Centre for Autism (ACCA), we conduct participatory and practice-oriented research on support for autistic children, adolescents, and adults and their family members. In our research projects we evaluate the effectiveness of supports and services.

www.academiccollaborativecentreforautism.be



ACADEMIC COLLABORATIVE CENTRE FOR AUTISM RESEARCH



PARTICIPATORY AUTISM RESEARCH

What?

ACCA is a collaborative network in Belgium funded by the Flemish government. Within ACCA researchers collaborate with autistic individuals, their family member, professionals and policy makers in a diverse range of research projects.

Why?

The ultimate goal of ACCA is to improve lifelong participation of autistic individuals in society.

What?

Participatory research involves the autistic community giving input and direction to research in an active and meaningful way. The views of autistic people are taken into account about: what research is happening, how the research is happening and what is done with the results.

Why?

To connect the autistic community and researchers and achieve shared goals.

Current practices for participatory research at the Academic Collaborative Centre for Autism

Within ACCA, we involve the autistic community in all phases of research. A unique concept of co-creation from start to finish. To this end, we cooperate with the Autistic Adults' Reading and Advisory Group (LAVA vzw) and the Flemish Autism Association (VVA). Autistic people are paid members of our steering committee, expert panels and project groups. This ensures that our research is and remains relevant to people with autism themselves.

RESEARCH PRIORITIES



At the start of a new round, we circulate a project call around different themes. These themes are chosen by the steering committee based on available research agendas drawn up by the autistic community.

Examples of research themes that the autism community considers important are: education & work, transitions, health & well-being, diversity and awareness.

PROJECT SELECTION



Many organisations submit project applications to us. We select from these applications based on the advice of the advisory group and four expert panels consisting of: 1) autistic adults, 2) parents of an autistic child, 3) professionals and 4) researchers.

Only projects considered relevant by the autistic community are chosen. The final decision is made in consultation with the steering committee.

RESEARCH DESIGN



Per selected project, a project group is composed with autistic adults (and parents). We ask the project group regularly to contribute ideas throughout the project.

We ask them for advice and feedback on the research design, the outcome measures, the autism-friendliness of research materials (e.g., informed consent form, questionnaires, interview guidelines).

The study design is then proposed to the steering committee.

DATA COLLECTION



Within our research projects, we collect data from autistic participants themselves through questionnaires, interviews and/or focus groups, wherever possible.

We also ask about their satisfaction with and feedback on the support or services we are evaluating.

What works well and should be retained? What does not work well and can be improved?

INTERPRETATION OF RESULTS



Once the data are in and we have done the initial analyses, we sit down again with the same project group consisting of autistic individuals (and parents) (see Research design).

We present the preliminary results. We then ask input of the project group on the meaning of and possible explanations for the results found.

COMMUNICATION OF RESULTS



We share our results with the general public in an accessible way using infographics. We ask the project group for their opinion on which results are important for whom and how best to communicate this information.

In consultation with the project, advisory and steering groups, we look at whether we can spread the support programs to other settings. The handbooks or guidelines are made available online so that everyone can start using them.