

AutWave 2019, Friday 1.11.

Main Programme

In Finnish and English, with translated materials

8.30-9.00 Registration

9.00-9.15 Opening words

9.15-10.00 Antti Kääriälä: The welfare of autistic people in the light of Finnish registry data (in Finnish)

Researcher Antti Kääriälä from the Finnish Institute for Health and Welfare discusses the well-being of Finnish people who have received an autism spectrum diagnosis in the light of registry data. There is a wealth of information stored in the registry databases of social and health services, as well as numerous other officials, regarding the users of the services. It is possible to utilize this data in research, which could provide answers to many questions that are otherwise difficult to tackle. Research data on the life situations of people diagnosed with ASD is currently sparse. Through research, it is possible to glean information from the registries concerning factors that influence life trajectories and well-being, among other things. Thus, registry research can offer much needed knowledge to support decision-making and advocacy.

10.00-10.45 Diederik Weve: The 'Onderzoeksagenda Autisme' study: Mapping the research priorities of autistic people in the Netherlands (in English)

The Autism Research Agenda (OZA) describes which subjects should be investigated according to (young) adults with autism (16+), parents of a child with autism (16-) and legal representatives of adults with autism and a serious need for care. 923 people participated in the study: 695 adults with autism, 166 parents and 62 legal representatives.

The initiator and project lead is Karin van den Bosch, who is also autistic. The results have been presented at events in the Netherlands and at the international Autism Europe conference.

10.45-11.00 Break

11.00-11.45 Johanna Kuisma: Goal- and function-oriented assessment of intervention needs in the context of the International Classification of Functioning (in Finnish)

The ICF classification system offers concepts and a conceptual hierarchy for issues related to a person's ability to function and guides us to consider functioning as a dynamic whole. With the help of ICF, the interactions between the different areas of functioning can be made visible as distinct entities, which means that they can be analysed in a structured manner.

ICF provides frameworks to both the process of reporting on functioning and to the interactions where information about functioning is exchanged. The framework results in structure in the information regarding functioning.

The aim to make information on functioning structured guides us towards being thorough in our mapping of functioning. Information that has been carefully collected and reported contributes to evidence-based decision-making. In evidence-based decision-making, the goal is to combine information on functioning with current research-based knowledge on intervention options, and to assess the suitability of different interventions with regard to the goal that has been set.

11.45-12.30 Riikka Lämsä: Finnish youth excluded from study and employment (in Finnish)

There were approximately 38,000 youth excluded from studying and employment in Finland in 2018. For some of these youth the situation becomes prolonged, which may lead to social and psychological problems. Some NEET youth have diagnosed or undiagnosed neuropsychiatric symptoms which exacerbate the difficulty of the situation. In this presentation, I will outline the number of NEET youth in Finland, the situations of these youth, and their ability to function. I will emphasize the service system: what tools does our current service system possess to help it identify, help and support NEET youth in their difficult situations.

12.30-13.30 Lunch

13.30-14.00 Jukka Kumpuvuori: Disability rights and the autism spectrum (in Finnish)

Legal Counsel Jukka Kumpuvuori has represented disabled people in legal matters since 2002, providing services to people with many different types of disabilities. In the past few years, increasing numbers of autistic people and parents of autistic children have sought help from him. In this lecture, Jukka will describe some examples of how autistic people have been helped, and could be helped, with the tools of legal advice and representation.

14.00-14.30 The Vave project and ASY peer groups: Discussion on disability rights (in Finnish)

Janne Fredriksson, coordinator of ASY's societal affairs discussion group and Emmi Varis, project worker of the Stability in Peer Support project, lead a discussion on topics that have emerged in autistic people's peer groups.

14.30-15.00 Coffee

15.00-15.45 *Parallel lectures:*

Yo Dunn: Putting autistic voices on the map (in English)

Autistics can find it very difficult to get our voices heard in discussions about public policies which affect autistic people. This lecture will draw on my experiences (including my involvement in the National Autistic Taskforce in the UK) to provide ideas and inspiration on:

- developing relevant knowledge and expertise

- making ourselves useful and establishing credibility
- effective targeting of opportunities and audiences for influence

As well as focussing on how we might exert influence most effectively, I will also argue that we should prioritise issues to influence, considering when doing so the importance of human rights issues and issues of particular relevance to autistic people who may be less able to advocate for themselves.

Henri Pesonen: Supporting employment of autistic university graduates (in Finnish)

Henri Pesonen will talk about the EU-funded project *Improving Employability of Autistic Graduates in Europe* (IMAGE), which studies and develops support forms and good practice to promote the studies and employment prospects of higher education students on the autism spectrum. The project started in October 2018, and it will end in August 2021.

In the current situation, too many students who are on the autism spectrum, or otherwise in need of support, drop out before they complete their studies or end up unemployed after they graduate. In addition to Finland, IMAGE has project partners in the UK, the Netherlands, France and Germany. Henri leads the collection and analysis of qualitative data for the project. IMAGE uses a participatory research approach of 'co-design', keeping the target group closely engaged in the planning and execution of research.

Side Programme

In English only

11.00-12.30 Leneh Buckle: Autistic stuckness (in English)

Workshop running in parallel with the main programme

Description:

Autistic people report a range of difficulties with starting and stopping activities which are often informally called 'inertia'. Considering how common these problems are, and how much of an impediment they can be to independent functioning, there has been nowhere near enough attention from researchers and clinicians. For the most part, they see these difficulties as 'non-compliance' or 'lacking (social) motivation' and go about trying to fix them.

I believe 'inertia', like autism itself, is actually a number of different underlying issues that overlap and end up sharing characteristics on the surface. In this workshop I will share some of what I think is causing inertia, because understanding these starting points can help find ways to overcome the difficulties. I will also share the many anti-inertia strategies I have developed and collected over the years. There will be an opportunity for the audience to share and discuss their own approaches.