

Autistic-led organisations
and groups in Europe:

(in)visibility across borders

The case of the ASY

What do *you* know about us? How would you find us, if you needed to?

The case of the ASY

Is anyone aware of

- how many members we have?
- how long our association has existed?
- what we offer to our members?
- what our goals and principles are?

The case of the ASY

- just over 240 members
- founded ten years ago (when an active community had already existed for about eight years)
- advocates for autistic individuals in Finnish society, aims to influence public opinion and policy
- constitution requires that at least half of the board members are autistic; in practice, all or nearly all are

The case of the ASY

- we organise regular peer group meetings in three cities and online
- we run several Facebook groups
- we organise two annual events: the Autistic Pride Day picnic and the 2-day Empowerment event
- we organise group excursions to theatres, exhibitions, sports facilities etc, subsidizing members' participation

The case of the ASY

- we are an active member in Autismiliitto, the national umbrella organisation in Finland, as the only autistic-led association among 23 parent-dominated ones
- two of our board members are also on the 9-member board of Autismiliitto
- we sometimes disagree with, and protest against, certain practices of Autismiliitto

The case of the ASY

- one of our board members is Chair of the National Disability Council
- we work together with parent-dominated autism associations on certain things: practical arrangements of our Empowerment event, planning leisure activities for teenagers and young adults

The case of the ASY

- we actively seek out other organizations that share our goals and commitment to autistic-led decision-making and advocacy

The case of the ASY

What we don't do (yet)

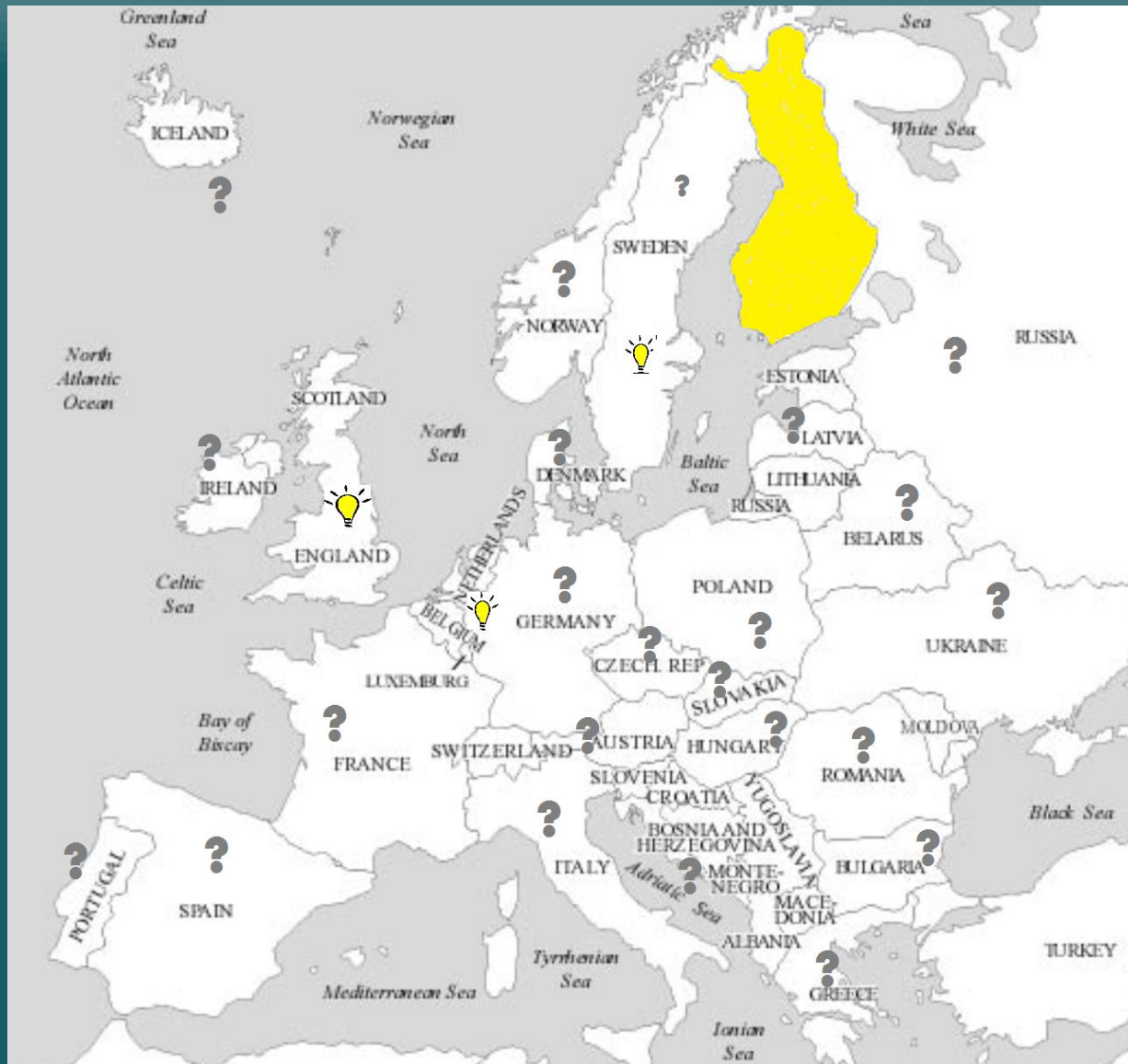
- highly visible public campaigning
- lobbying
- close contacts with researchers
- employing staff
- running our own funded projects

International networking

What we could see a year ago

- recollections of visitors from several countries, in the late nineties and ten years ago
- a constant stream of discussion, opinions, ideas from English-speaking countries
 - not much about what kinds of groups or organizations might be behind it all
- some websites and discussion forums: the Netherlands, Germany, Sweden
 - very little about how big, active or stable the groups might be

The mental image



International networking

What we can see now – examples

Organiserade Aspergare, an all-autistic association, running its own project, **Autistiskt Initiativ**, to promote employment prospects in Sweden

VildmarksAutisterna, an association for autistic people who enjoy the wilderness

Eesti Aspergeride Ühing, a small but growing organization of autistic adults in Estonia, running group meetings in two cities

The **Neurodiversity in Russia** website and community, operating in the Saint Petersburg region, speaking for the rights of LGBT autistic people in Russia

International networking

What we can see now – examples

The [aspergers.ru website](http://aspergers.ru), run by autistic Russians

The [Our Sunny World support group](#) for adults in Moscow, run by the young autistic researcher Alexey Voskov

The [“Vykhod” fund and project](#), setting up the first centre in the country to provide services and support for autistic adults and their families

Another mental image



International networking

What else we can see –

- individuals working within these organizations, their skills and personalities
- some of the most current issues to be solved in their countries
- a variety of attitudes, ways of constructing identities, both within these organizations and in the societies where they function

International networking

What else we can see –

- A growing number of autistic-led organizations that want to reach out to each other, learn from each other, form a network, perhaps even an international organization
- Roderik will tell you about some of the lights that are on in other parts of Europe

Links and references

Suomen Aspergeryhdistys: <http://www.asy.fi>

“Kinkkukiusaus” (“Ham casserole”), an experimental horror film by the ASY film group:

<https://www.youtube.com/watch?v=QeuLod6qQPw>

FB event *Empowerment-päivät*:

<https://www.facebook.com/events/379255035796437/>

FB group *Autism Spectrum in Finland* (for English speakers):

<https://www.facebook.com/groups/141323396292579/>

Links and references

Organiserade Aspergare: <http://www.aspergare.org/>
VildmarksAutisterna: <http://www.vildmarksautisterna.se/>
Eesti Aspergeride Ühing: <https://aspiyhing.wordpress.com/>
Aspergers website: <http://aspergers.ru/>
Our Sunny World: <http://www.solnechnymir.ru/>
Neurodiversity in Russia: <https://neurodiversityinrussia.com/>
“Vykhod” fund and project: <http://outfundspb.ru/wp/>

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<https://brocku.ca/maplibrary/maps/outline/other/EUROlocator2.jpg>
(Accessed October 3, 2016).