autistic lead initiatives in the Netherlands

diederik Weve (Shell, chairman PAS, projectlead Autminds)

- Autism self-advocacy in the Netherlands: past, present and future, Mitzi Waltz, Karin van den Bosch, Hannah Ebben, Lineke van Hal and Alice Schippers, *Disability & Society*, 2015 Vol.30, No. 8, 1174-1191 http://dx.doi.org/10.1080/09687599.2015.1090954
- 🛭 www.pasnederland.nl
- & www.autismetentop.nl
- & www.autismeambassade.nl
- & www.autminds.nl
- <u>www.ietsdrinken.nl</u>
- & www.autiroze.nl

- & Autistic Self-advocates have been active since 90's
- ន goals:
 - a self-understanding,
 - a improving image,
 - a access to appropriate social activities, employment and services
- ø they have achieved some goals
- ø barriers:
 - n lack of support from other organisations
 - a problems with governance
- Better support and equal coalitions with other groups could help them to be more effective

from: Autism self-advocacy in the Netherlands: past, present and future

- mail-groups (1990's 2001) → PAS & Autsider Forum
- & Vereniging Personen uit het Autisme Spectrum PAS (2001...)
- & Autsider forum (2001...)
- & Autisme Ten Top work-related image campaign
 - 🛪 LinkedIn forum for autistics & care/support-professionals
- - monthly networking event using standard format (15 cities)
- & Autisme Ambassade (2013..) autistic colleague change agents
- & Autminds (2014...) yearly conference
- & AutiRoze (2016...) LGBTI intersectional group (6 cities)

main autistic lead initiatives in NL

- & 2001 formed as student group. joined and left NVA
- ≥ >500 paying members
- & Self-advocacy
 - ø identify and vocalise needs before others do
 - ø participate in initiatives, R&D groups
 - a Care-Standard Autism
 - A Academic Workshops Reach-Aut & Samen Doen (AWA)
 - n Investigates research needs according to non-professionals
- & Social Activities
 - ø networking events (20 cities)
 - ឆ self-help groups (16 cities)
- & Knowledge development
- & Information & Education

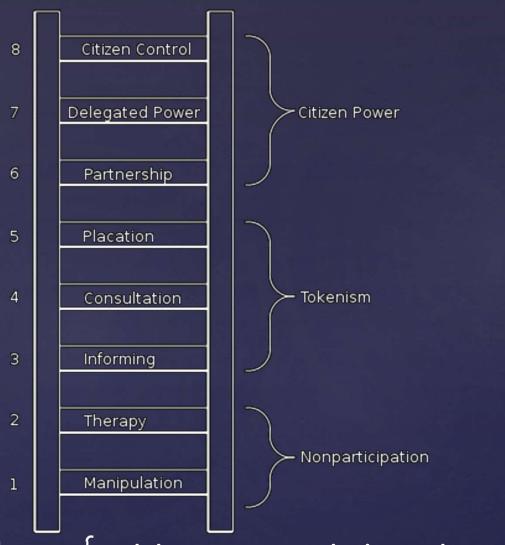
PAS (Society of Adult Autistics)

- & conference run by and for autistic adults
 - ø theme, subjects and content
 - ø boundary conditions (accessibility)
 - ิ inclusivity for non-autistics
 - σ 3 year growth 60 \rightarrow 150 participants
- Replatform for sharing of ideas and knowledge
 - g voice
 - ิ practical experience
 - ø knowledge & science (preferably -non-medical aspects)
 - \$\pi\$ 15 lectures, workshops, discussions etc
- k modelled after Autscape
- & collaborating with HvA (higher education social work)

Autminds

- & flexibility in communication & cooperative styles
- & variability in energy/loadability
- k managing conflicting needs
- k not access to government funds for patient-organisations
- & scarcely positions in / access to board levels
- k tokenism is not recognised by most autistics

it's not simple to work with autistics



Ladder of citizen participation

(Sherry R. Arnstein, 1969)

