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# AN ORGANIZATION RUN BY PEOPLE WITH AUTISM: PROBLEM OR POWER?

*KARIN VAN DEN BOSCH*

Karins |  
Consultancy

**DISABILITY STUDIES**  
in Nederland

# PROGRAMME

- About me
- About our team
- About our research
- About PAS
- About Consumer-Run Organizations
- About our research results
- About you

# ABOUT ME

- Junior researcher DSiN / Metamedica – Vumc
- Independent writer and expert-by-experience
- Owner of Karins Consultancy
- Academic background in medical and organizational science
- Several non-academic publications about autism and topics of interest to adults with au
- Asperger diagnosis

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# ABOUT OUR TEAM

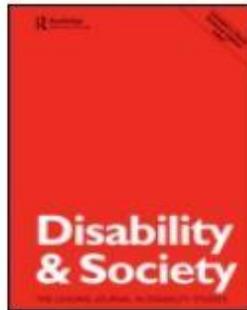
- Lineke van Hal, PhD (*HAN SOCIAAL Research Centre for Social Support and Care in the Community, HAN University of Applied Sciences, Nijmegen, the Netherlands*)
- Mitzi Waltz, PhD
- Hannah Ebben
- Alice Schippers, PhD
- (*Disability Studies, department of Medical Humanities, VU University Medical Center, Amsterdam, the Netherlands*)

**DISABILITY STUDIES**

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# ABOUT OUR RESEARCH

- Two (related) qualitative research projects
- 1) *Autism self-advocacy in the Netherlands: past, present and future*
- 2) PAS-Nederland: a consumer-run organization by and for adults with autism in the Netherlands



Disability & Society



ISSN: 0968-7599 (Print) 1360-0508 (Online) Journal homepage: <http://www.tandfonline.com/loi/cdso20>

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

Mitzi Waltz, Karin van den Bosch, Hannah Ebben, Lineke van Hal & Alice Schippers

To cite this article: Mitzi Waltz, Karin van den Bosch, Hannah Ebben, Lineke van Hal & Alice Schippers (2015) Autism self-advocacy in the Netherlands: past, present and future, *Disability & Society*, 30:8, 1174-1191, DOI: [10.1080/09687599.2015.1090954](https://doi.org/10.1080/09687599.2015.1090954)

To link to this article: <http://dx.doi.org/10.1080/09687599.2015.1090954>

# ABOUT PAS-NEDERLAND

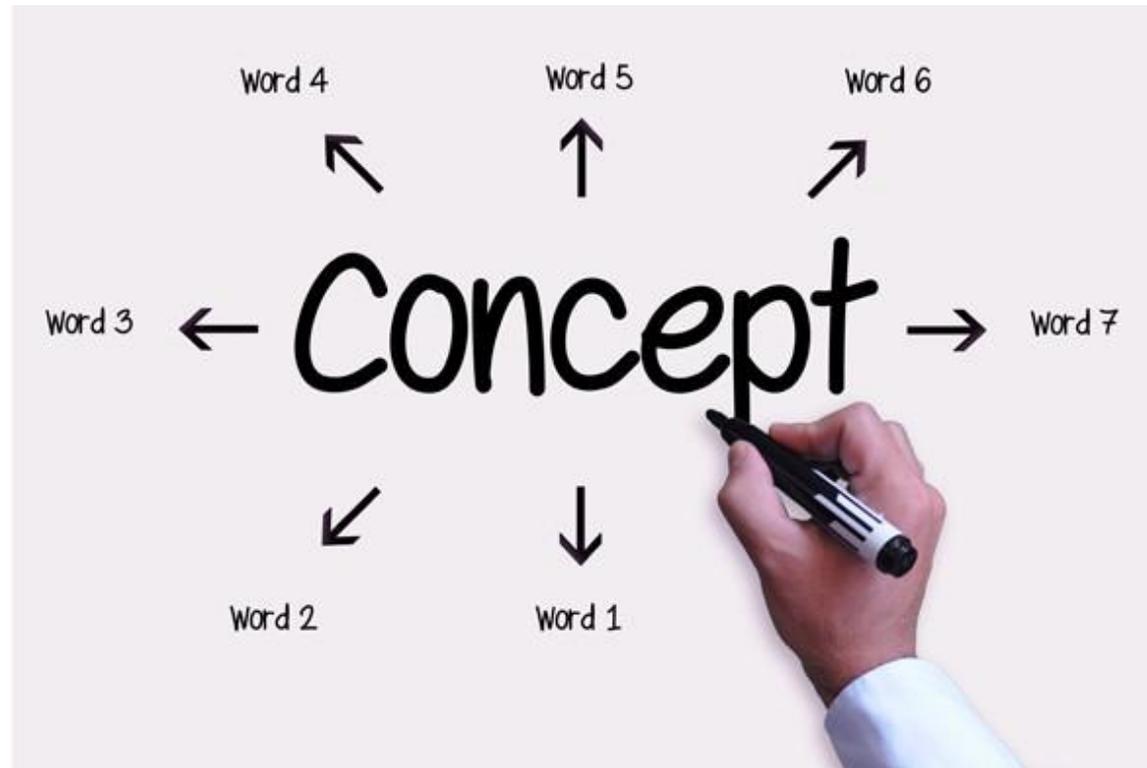
- An organization by and for adult Persons on the Autism Spectrum in the Netherlands
- Since 2001
- Currently about 600 members, presumed supporters ('achterban') larger
- Approximately 20 peer-support groups, 20 peer-contact days/year, advocacy working group on housing
- In the past: working groups on mental health care; employment
- Run by volunteers with autism



# ABOUT PAS -2

- PAS is an organization. But what kind of organization?
- How to describe this kind of organization in scientific terms?
- What concepts should we use?
- *How to describe an organization run by people with autism?*

# CONCEPTS, CONCEPTS AND MORE CONCEPTS



Several terms in the literature with different meanings fall under the mental health self-help umbrella, including mutual-help groups (e.g. Corrigan et al. 2005), mutual support groups (e.g. Chien et al. 2006), mutual aid groups (e.g. Kelly et al. 2004), self-help groups (e.g. Burti et al. 2005), consumer-run organizations (e.g. Brown et al. 2007), consumer/survivor initiatives (e.g. Nelson et al. 2001), consumer drop-in centers (e.g. Mowbray et al. 2002), consumer-operated self-help centers (e.g. Swarbrick 2007), self-help agencies (e.g. Segal and Silverman 2002), peer-run organizations (e.g. Clay 2005), consumer-run businesses (e.g. Kimura et al. 2002), self-help programs (e.g. Chamberlin et al. 1996), consumer-delivered services (e.g. Salzer and Shear 2002), and consumer-run services (e.g. Goldstrom et al. 2006). Although it is impossible to place these different initiatives into tidy categories, it is useful to conceptualize them along two continuums: (1) a continuum of organizational structure; and (2) a continuum of organizational focus.

**Self-Determination for People with Developmental Disabilities and Autism: Two Self-Advocates' Perspectives**  
Michael J. Ward and Roger N. Meyer  
*Focus Autism Other Dev Disabl* 1999 14: 133

# The Effect of Professional Partnership on the Development of a Mutual-help Organization

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## Consumer-run services research

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# Organizational Capacity Needs of Consumer-Run Organizations

Scott Wituk · Chi C. Vu · Louis D. Brown ·  
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The Impact of Professional Partnerships  
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Consumer-run services research

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Autism: Two Self-Advocates'

- 
- Peer-support organization
  - Self-help group
  - Self-advocacy organization
  - Client initiative
  - Association of autistic individuals
  - Patient/client organization
  - Social movement
  - Disabled people's organization
  - Ex-psychiatric patients movement
  - Consumer/survivor initiative
  - Consumer-run services
  - Consumer-run organization

# ABOUT CONSUMER-RUN ORGANIZATIONS

- A consumer-run organization (CRO) is an organization that is governed and staffed by people with a (serious) mental illness.
- Many people with a mental health condition use or have used mental health care services, the so-called 'consumers', so these organizations are called consumer-run organizations.

# CONSUMER-RUN ORGANIZATIONS

- One fundamental criterion:
- All final decision making lies in the hands of consumers (a.o.: Brown et al. 2008; Wituk et al. 2008)
- ‘Nothing about us, without us’ is the defining objective
- Members are allowed to participate in organizational decision-making and governance (Segal & Hayes, 2016)

# CONSUMER-RUN ORGANIZATIONS

- Two main orientations:
  - 1) Self-help and peer support
  - 2) (Self-)advocacy
- They aim at individual change (empowerment) and/or institutional change and/or social change (e.g. improving housing and employment conditions)

# CONSUMER-RUN ORGANIZATIONS

- Important values (Brown, Shepherd & Wituk 2007):
  - Empowerment; promotion of inner strenghts
  - Peer-support, helping each other
  - A sense of community, belonging
  - Participation
  - Self-acceptance and openness

# CONSUMER-RUN ORGANIZATIONS

- Problems mentioned in the literature about CRO's:
- Heavy reliance on volunteers with a high volunteer turnover
- Lack of management and technical skills (leadership skills etc.)
- Internal discussions over directions
- Organizational instability and organizational crises

# ABOUT OUR RESEARCH RESULTS

- Based on my personal experience at PAS (and also at other autistic-led organizations, like Autminds)
- Interviews with 8 key persons (mostly staff and board members of PAS)
- Additional data about PAS, e.g. annual reports



*“I think that certain coordinating qualities, which has also to do with putting a certain structure down, a certain order, there are too little people at PAS who have these qualities.”*

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*“You don’t only have to deal with each others good sides, but also with all those disadvantages: the communication difficulties, the misunderstandings, the incomprehension, don’t see what the other person needs, don’t tell what you need yourself, don’t be able to tell this because you are not aware of your own needs. In this we are too limited as a human being. And then, in addition to this, you need to know how to manage an union, because that’s not a sinecure, euh..No.”*



*“Getting things done, getting people to form their own group of people, to get those who can do the jobs you need to have an association like that. Most people with autism are just waiting for things to come, they don't really want to involve themselves. Most know that they simply couldn't do everything that's necessary. They know from themselves that they are unreliable performing under pressure, so. Yeah, I think that's simply the problem.”*



*“If you talk about ‘by and for’ and you talk about how can we deal with the limitations we have as a group in a realistic way, are we together capable, because one person scores bad at A, another person at B and a third at C, but together mutually neutralizing, can we cooperate in this way or are the individual limitations so big that their combination never exceeds them? (..) I think that our individual limitations added together never will transcend. That is just..that’s inherent in the limitation: it limits you. (...) Don’t act like you can do it as a group, where you can’t do it individually.”*

# ABOUT OUR RESEARCH RESULTS

- Main problems:
- Problems with management, leadership and coordinating tasks
- Problems with decision making (conflicts over directions, many discussions)
- Problems with getting things done
- Problems with (organizational) continuity

# CONSUMER-RUN ORGANIZATIONS

- Possible solutions???
- Non-autistic people, for instance health care workers, support workers or NVA-employees in the management, leadership or coordinating positions....

# CONSUMER-RUN ORGANIZATIONS

- Back to the literature about CROs:
- Professional assistance and support:
  - -danger to lose equality and power-sharing settings
  - -danger to lose the 'lived experience' model where CROs are based upon

# CONSUMER-RUN ORGANIZATIONS

- Back to the literature about CROs:
- “It is important for mutual-help organization leaders and professional partners to recognize that, even in the most favorable circumstances, close collaboration is likely to lead to change in the unique structures and processes of mutual-help groups” (Salem 2008).

# CONSUMER-RUN ORGANIZATIONS

- Back to the literature about CROs:
- “Consumer-control, while a necessary condition for a CRS, is not a sufficient condition to ensure that the organisation’s empowerment ideology and its major contributions to client outcomes will be carried into practice. (...)”
- A consumer operated service without its empowering approach may be no more than cheap care at best, not an agency within the conceptual and operational achievement of the mental health consumer movement’s founders (Segal & Hayes 2016)”.

# ABOUT PAS-NEDERLAND

So, where to go with PAS-Nederland?



# QUESTIONS?

Any questions, comments or thoughts?

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