

# Agency in the twenty-first century: the emperor's new clothes

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# Aim

- Changes in policies emphasize self-determination (agency) as important outcome

*“We want adequate high quality humane care, client-centeredness and freedom of choice”*

Having agency is prompted as a crucial factor to shape the responsibility to participation

- But, what is meant with agency?

- To perform a literature search on agency and related constructs (including Dutch policy documents)

# Searches

- Mastery / Self-mastery
- Empowerment / Self-empowerment
- Agency / Self-agency

Related constructs popped up:

~~Resilience / Fight (people) (blank)~~  
~~Self-efficacy (people) (blank)~~

# Dimensions to assess the constructs

- Internal or external (eg, from within the person)
- Includes skills/competences or not
- Value free or not

# Some examples

Empowerment:

*“Individuals’ capacity to make decisions about their health (behaviour) and to have, or take control over aspects of their lives that relate to health”* McAllister, 2012

Internal

Includes competences

Not value free

And: restricted to health

# Some examples

Internal empowerment:

*“Someone should be helped to empower himself to perceive control”* Emener, 1991

External (should be helped)

No competences

Not value free

# Some examples

Self-mastery:

*“Perception of actual power to bring about  
desired outcomes”* Marshall & Lang, 1990

Internal

No competence

Value free

# Summary

- Most constructs refer to external forces or perceived needs, exclude necessary competences, are not value free (more=better)
- However, agency originally was personal, relating to individual needs and meanings



- The Independent Living Movement:  
“[Agency refers to] having control over one’s life, based on choice options between acceptable alternatives facilitating meaningful choices in daily life” (DeLoach, Wilkins, and Walker 1983)

# However...

- Agency now appears to be an outcome instead of a mean
- From “*citizen’s own power*” to “*you shall do*”
- Meanwhile support facilities to shape agency are more and more withheld
- The call for agency similar to the emperor’s new clothes

# Trying to find an explanation

- True capacities maybe insufficiently acknowledged?
- An 'external' viewpoint
- And: missing a model of what constitutes agency!

# Towards a link between agency and skills

- Disability Management (Bellemakers, 1999)
  - Interpersonal roles
  - Information roles
  - Decisive roles
- Contextual
- Required skills
- From required skills to needed support!

# Discussion

- Relevance for people with chronic conditions
- Relevance for policy makers
- Relevance for researchers
- Relevance for support systems / healthcare



# Questions

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