



DWARSLAESIE
ORGANISATIE
NEDERLAND

Dutch SCI lobbying: examples catheters & wheelchairs

**Dutch SCI Association
ESCIF, Gothenburg, 28 May 2019**

DON = Dutch SCI Association



- The only national stakeholder for people with a SCI
- Founded in 1976
- Voluntary organization / some paid support
- Now over 1.500 members
- Three core tasks:
 - Information provision
 - Advocacy
 - Peer support

DON advocacy



- Long tradition in the Netherlands
- Both nationally and (where necessary) regionally
- Advocacy mainly regarding:
 - health care (SCI) policy and laws
 - health insurance reimbursement
 - treatment guidelines in rehab, neurology, urology, orthop. etc.
- Own initiative / by or as repres. of Dutch umbrella organ.
- Because of experience: asked to take part

DON lobbying



- Lobbying mainly on more ‘practical issues’
- What by DON? – what by Dutch umbrella organisation?
- For example by DON:
 - professional SCI peer support on 8 SCI rehab departments
 - research agendas in (SCI) rehab, neurology, orthop. etc.
 - appointed SCI professor
- Or regarding devices for people with SCI
- Today 2 examples: catheters and wheelchairs

Example catheters



- Catheters reimbursed by health care insurance
- Health care insurance mandatory in NL
- Health care insurance package: annual political consideration
- Annual advise by government agency: Dutch HC Institute (ZiN)
- Dutch Patient Federation has 2 seats in ZiN commission
- DON board member occupies 1 of these 2 seats

Example catheters (cont.)



- During recent crisis years: idea to limit number of reimbursed catheters and/or maximum amount of money per day
- Major adverse consequences: qualitatively and financially
- DON initiated report: need for sufficient & adequate catheters
- Writers report: external experts, incl. urologists & inc. nurses
- Report showed: cut back idea is ‘penny wise pound foolish’
- Now advise SCI inc. nurse is binding for health care insurer

Example wheelchairs



- Social Support Act (Wmo): max. participation in society
- Wmo since 2015, decentralization from national to local
- Help living max. independently at home, home adaptations, individual transport and supportive devices
- Among which: everyone is entitled to a wheelchair
- Cheapest adequate provision, no own payment (is an exception)

Example wheelchairs (cont.)



- Wmo is implemented by (now) 355 municipalities
- Not all solo, there are regional municipal partnerships
- In practise: great diversity between municipalities
- What is cheapest adequate provision?
- Major differences in coverage for people with SCI
- People go to court: not the right wheelchair was covered

Example wheelchairs (cont.)



- DON is member of Ieder(in), the Dutch umbrella organisation for people with disability or chronic illness (250 member organ.)
- DON asked Ieder(in) to start Wmo discussion with VNG
- VNG (Dutch Municipalities Association) has no 'power', makes model regulations / model contracts for its members
- Report external experts: its 'penny wise pound foolish' if not adequate wheelchair but standard wheelchair is provided to people with SCI
- VNG made new Wmo model regulation: advice SCI specialized therapist about required wheelchair is best taken into account by municipality

Questions? / discussion?

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