



DWARSLAESIE
ORGANISATIE
NEDERLAND

Dutch / DON examples of political work

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DON = Dutch SCI Association



- The only national stakeholder for people with a SCI
- Founded in 1976
- Voluntary organization / some paid support
- About 1.650 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.

Dutch umbrella organizations



- Dutch Patient Federation: 56 members, active in 'cure'
- Ieder(in): 238 members, active in 'care' for people with a physical / mental disability or chronic illness.
- UN Convention on the Rights of Persons with Disabilities (CRPD): particular area of focus of Ieder(in)
- DON active member of both Dutch umbrella organizations
- Because of DON experience: asked to take part

DON lobbying



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

Examples 'practical issues'



- Catheters reimbursed by health care insurance
- During crisis years: idea to limit number of reimbursed catheters and/or maximum amount of money per day
- DPF-DON lobby/report: 'penny wise pound foolish' was successful
- Wheelchairs = Social Support Act (Wmo) = local decisions: cheapest adequate provision, no own payment (is an exception)
- Report external experts: its 'penny wise pound foolish' if not adequate wheelchair but standard wheelchair is provided to people with SCI
- new Wmo model regulation: advice SCI specialized therapist about required wheelchair is best taken into account by municipality

Examples 'practical issues' (cont.)



- Physiotherapy: idea to make cuts in chronic care
- Problem; no proven effectiveness in chronic SCI care
- Petition chronic users persuaded insurers: postponement
- Home adjustments: national improvement agenda Wmo
- Newly injured 'stuck' in rehab.centre: home adj. takes too long
- Coalition patients, rehab.centres & insurers: common interest

Political influence in NL



- Dutch Patient Federation and Ieder(in) are in the lead
- DON initiates or supports national actions
- The influences of patients interest has increased
- Direct contact with MP's and they raise issues in parliament
- And sometimes you are lucky:

Otwin van Dijk, DON member
SCI since he was 18
MP PvdA (Labour Party) 2012-2016
January 2016 ratification CRPD in NL

Now president Dutch Patient Fed.
and CEO big regional general hospital



UN CRPD the Dutch way



- CRPD since 2006-2007
- Ratification in NL in 2016, mainly because of:
 1. National railways: in 2030 accessible trains and the platform heights have been adjusted at 337 stations
 2. No enforceable rights regarding fully (wheelchair toilet) accessible (privately owned) cafes and restaurants
- Use parliamentary debate on the progress of national CRPD implementation (mandatory every 5 years)

Questions? / discussion?

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