Disability Management as effort to shape citizenship

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Background

- People with childhood-onset disabilities close to normal life-expectancy
- Adult life comes along with health issues (eg, pain, fatigue, walking deterioration) and participation restrictions (eg, leisure, employment)

Hilberink, van der Slot & Klem. Disability & Health Journal 2017; 10:361-366.
Benner et al. Developmental Medicine & Child Neurology 2017; 59:762-768.

Citizenship

▸ An ambigious concept
  ▸ Civil rights (*juridical citizenship*)
  ▸ Societal functioning (*social citizenship*)
    ▸ Inclusion?

Gilbert, Cochrane & Greenwell. International Journal of Social Welfare 2005; 14:287-296.
Albrecht. Encyclopedia of disability. Thousand Oaks/London/New Delhi: SAGE Publications, 2006.

Citizenship

▸ A dimensional approach
  - ▸ Formal status (*juridical*)
  - ▸ Democratic practice (*social norms, an actor in society*)
  - ▸ Identity (*being part, belonging*)

Council for Public Governance. Ethnicity, binding and citizenship. The Hague: SDU, 2001.

Citizenship

‣ Defined by citizens
  ‣ Contribution (*looking out for others, helping people, give something back to society*)
  ‣ Inclusion (*belonging, taking part*)
  ‣ Equal opportunities (*rights, having control, autonomy*)
  ‣ Barrier-free context (*no negative attitudes / stigma, having social relationships*)

Yeung, Passmore & Packer. Journal of Intellectual & Developmental Disability 2008; 33:65-75.

A welcome society / UN Convention

Society needs to take action

Citizenship

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Citizen can act on this

Disability Management

Disability Management

▸ Survival and director's efforts to shape societal functioning

▸ Three domains
  ▸ Inter-personal roles
  ▸ Information roles
  ▸ Decisive roles

Bellemakers. Versie, Tijdschrift voor Gezondheid, Burgerschap en Politiek 1999; 17:Cahier 1.

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Strategies

▸ Part of citizenship requires Disability Management

▸ Five strategies of adults with childhood-disabilities (aged 50 years or older) to deal with health problems while upholding citizenship

Jedeloo et al. TVZ 2017-4: 46-49.

Energy management

'When you go somewhere today, you take a rest day tomorrow to maintain balance.'

Taking initiative

'You are always busy to come up with solutions to make it as easy as possible for yourself.'

Self-help with support

'For two weeks, we started an experiment with eHealth. [...] with your Ipad, you'll get in touch with the nurse so you can discuss the problem and she asks how can we help you.'

Learning from peers

'If I had known things sooner, I would have done otherwise. Just as you say about dealing with reduced energy levels. I should have done that 30 years ago. [...] I have already indicated that I want to have an annual check-up in a rehabilitation center ... because I do not really know myself.'

Medical monitoring

'Peer contact is valuable, you learn from each other. It proves that you're not the only one with questions.'

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Jedeloo et al. TVZ 2017-4: 46-49.

Energy management & Medical monitoring

‣ Information roles:
  ‣ Observer – How do I feel, am I OK?
  ‣ Sender – Communicating changes/disruptions
‣ Decisive roles:
  ‣ Manager of disruptions – Taking care and dealing with reduced energy levels/ scheduling visits to healthcare providers / support staff
  ‣ Consumer – Chosing the adequate healthcare providers / support staff / helping aids

Bellemakers. Versie, Tijdschrift voor Gezondheid, Burgerschap en Politiek 1999; 17:Cahier 1.

Taking initiative & Self-help with support

▸ Inter-personal roles:
  ▸ Leader – Organizing optimal care and support
  ▸ Liaison – Maintaining network to optimize care and support
▸ Information roles:
  ▸ Observer – Where to find relevant info and resources?
  ▸ Spokesmen – Advocating your interests and rights
▸ Decisive roles:
  ▸ Entrepeneur – Re-inventing ways for care and support
  ▸ Consumer – Chosing the adequate healthcare providers / support staff / helping aids

Bellemakers. Versie, Tijdschrift voor Gezondheid, Burgerschap en Politiek 1999; 17:Cahier 1.

Learning from peers

- Inter-personal roles:
  - Liaison – Maintaining network to meet peers
- Information roles:
  - Observer – Where to find relevant info and resources?
  - Spokesmen – Advocating your interests and rights

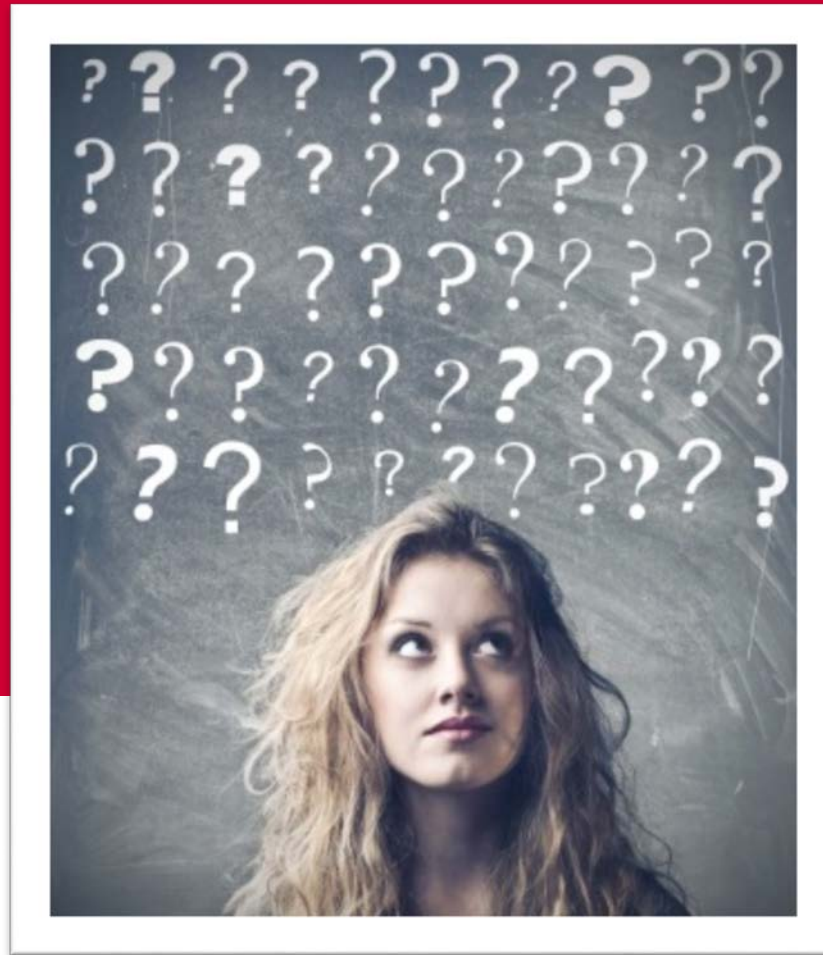Bellemakers. Versie, Tijdschrift voor Gezondheid, Burgerschap en Politiek 1999; 17:Cahier 1.

Key findings

▸ Adults with childhood-onset disabilities apply effective strategies to stay connected with society and prefered roles (citizenship)
▸ Citizenship is <u>partially</u> 'do-able'; Disability management can be a model to support this.

➜ Support should enable control!

Implications

- From a citizenship perspective, policy-makers should acknowledge the required disability management roles to *shape* one's citizenship

- Supportive strategies for these roles need to be developed AND implemented

- More focus on living with disability than on impairments itself

Are there any questions?