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**Workshop on
Long-Term Care
needs assessment
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Assessing Needs in LTC

An European overview of concepts and issues

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Summary

- Defining need in LTC

- Some policy trends

- Examples from the EU: empowerment of users, carers' needs, standardisation and 'carer blind' needs

- Conclusions/questions for debate

Defining need in LTC

Defining LTC (based on WHO 2003, Colombo et al 2011, Rodrigues et al 2012):

*Ensure the maintenance of the best possible **quality of life**, with the **greatest possible degree of <u>independence</u>, autonomy, participation, personal fulfilment and <u>human dignity</u>**.*

What are needs in LTC (Norton 2000, Kane 2001, Bowers et al. 2001)?

- **Care vs cure**

- **Long-term** care: continuity, end point?

- ***Quality of life*** vs mortality or health related quality of life

- **Interpersonal** experience of users: user as co-producer of care

Theory meets policy: recent developments

- Capabilities (Sen, 1993)
- **Patient-Reported Outcome Measures** (Schalock, 2004)

- **Quality of Life**
  - Multi-dimensional: **physical, psychological and social dimensions**
  - *Determinants: physical/built environment, social, culture, individual*
  - **Different people value different things in QoL**

- **Disability** movement **→ Agency** and **empowerment**
- **Feminist** critique **→ Carers**

Variations of 'need' across Europe

Formal care in percentage of 65+ with care needs
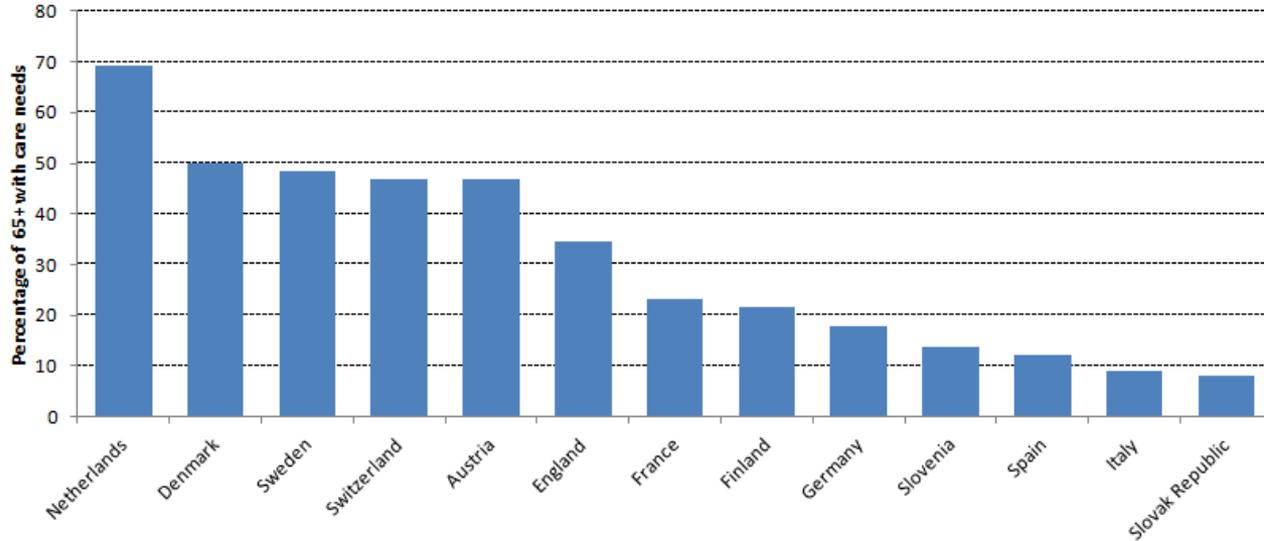
Source: Rodrigues and Nies (2013), based on SHARE, OECD *Health Database* and INTERLINKS national reports
Care needs refers to those with at least moderate self-reported activity limitations.
Figures for Austria are over-estimated as beneficiaries include 60+.

Participation of users in assessing needs

- Background: disability advocates claim not just for cash but control over needs
- The *Individual Budget* experiment (2006-2008)
- Self-assessed needs supported by care worker → *what* and *how*
- Mainstreamed into the Personal Budgets (2013)

- Insights from the assessment (Glendinning et al 2008, Moran et al 2013)
- Supported environment for need assessment
- Risk management and professional *ethos*
- Needs without sufficient resources

- **Trade-off: empowerment vs acceptable use of public money**

Assessing needs … of carers

- Identifying carers in the system (UK, FR, HU, LU, MT, NL and SW)
- Assessment of care needs independent of users (UK, SW and MT)
- A 'weak point' in European social model (Courtin et al 2014)
- Recognising complementary but also specific needs of carers
- "Recognised, Valued and Supported: Next Steps for the Carers Strategy" (UK)
- Care leave, respite, services → Employment, mental health, social inclusion

- **Trade-off? Needs of users vs needs of carers**

Further initiatives, trends and issues

- ***DK: Preventive home visits to 75+***
    - Mandatory visits (2x year): assess resources, maintain independence
    - Mixed evidence of impact on delaying disability (Vass et al 2006)

- ***Standardisation of assessment (DK 'Common Language', SK, NL)***
    - Increased transparency, reduced discretion (DK) and inequalities (?)
    - Multi-disciplinary assessment (SK)
    - Taylorization of tasks and possible "time-trial" care (Roostgard et al 2011)

- ***(Non) 'Carer-blind' assessment (UK, NL)***
    - 'Customary care' (NL) and household composition → gender/class implications

- **Trade-offs: transparency vs standardisation; ↑ take-up = ↑ public expenditure**

Needs assessment as a crucial steering mechanism

- **Political choice**
  - The definition of LTC needs will always have a political bias

- **Gate-keeping**
  - To keep control of 'new entries' into the system
  - Example: raising the minimum threshold of needs for eligibility (Austria)

- **Supporting the entry to the LTC system**
  - Care counselling and information about services and opportunities in case of LTC (users and carers) (South Tyrol)
  - Assessment in the home of the beneficiary and in presence of the main carer (Austria, Germany, South Tyrol)
  - Lower threshold for eligibility (Austria vs. Germany)
  - Information campaigns, LTC hot-line (Austria)

- **Trade-offs: prevention vs reaction; ↑↓ take-up = ↑↓ public expenditure**

Conclusions and questions for reflection

- **Frailty** as a **social construct** dependent on *capital*
- Focus on **quality of life**

- What's the balance between empowerment, transparency and equality?
- Are we prepared for participation of user in assessment of needs?
- What needs can we afford to meet?
- Informal carers: part of the need or a need of its own?

Thank you for your interest!

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