

The identity of long-term care: Values, missions and definitions

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Why is identity important for the construction of a LTC system?

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Identity: the conception and expression of ...
individuality or group affiliations

“A society that treats its most vulnerable members with compassion is a more just and caring society for all.” (WHO, 2002)

LTC is about people:

- people as clients/consumers/users
- people as relatives and family/informal carers/volunteers
- people as formal care service providers
- people who make policy, plan, manage and deliver care services

*i.e. Need for a **value system** that embraces all these stakeholders (trust, respect, dignity, equality etc.)*

LTC as an incipient system

- **Formal LTC:**
Health care – **Long-term care** - Social care
- **Informal LTC:**
Relatives, friends, volunteers
- **Migrant care workers**
***BUT** blurring of boundaries between formal and informal sectors has created a “mixed care workforce” consisting of*

“Mixed care workforce”

- **Informal Carers** – untrained/trained, paid/unpaid, working alone/ working with formal carers, social security (health, pension contributions covered)/ or not
- **Migrant Care Workers** – untrained/trained; working in residential care/ home care; legal (social security contributions/health/accident insurance) or illegal (“black-market” risks, but cheaper)
- **Formal Caregivers** – health and social care professionals, including new professional groups (care assistants; care/case managers)
- **Volunteers** – variable role in different countries – 2011 EY Volunteering (<http://www.age-platform.org>)

Family and state: Who has main responsibility for the care of dependent older people (OP)?

Findings: Variations between countries in relative **legal responsibilities**, leading to wide disparities in their related LTC care policies and practices, as well as in the role of informal carers-ICs (3 main models):

- **Family** has first legal responsibility for financial support (EL, ES, FR, IT, SK), although unclear for provision of practical care - **BUT** *some recent legislation and measures to support ICs in most countries*
- **State/municipalities** explicitly responsible for care at full cost (SE) - **BUT** *“rediscovery of family care” and municipal obligations to support ICs*
- Responsibility for, and rights to, care are given to **dependent OP** via the “deposit” of compulsory LTC insurance (DE) - **BUT** *full costs of care not provided for, so ICs fill the gaps*

Values: some definitions

- “... broad preferences concerning appropriate courses of action or outcomes.”
- “Values reflect a person’s sense of right and wrong ... and tend to influence attitudes and behavior.”
- “Personal Values provide an internal reference for what is good, beneficial, important, useful etc.”

Different stakeholder perspectives on relative importance of values in LTC

Examples:

- Older person – relationship with caregiver
- Informal carer – respect for older person
- Service provider – respect for older person, provision of good care
- Manager – efficiency, value for money
- Policy maker – political ideology

The “Vision of INTERLINKS”

- to improve long-term care for older people, through linking informal and formal care systems in a shared provision of care
- The INTERLINKS framework ...

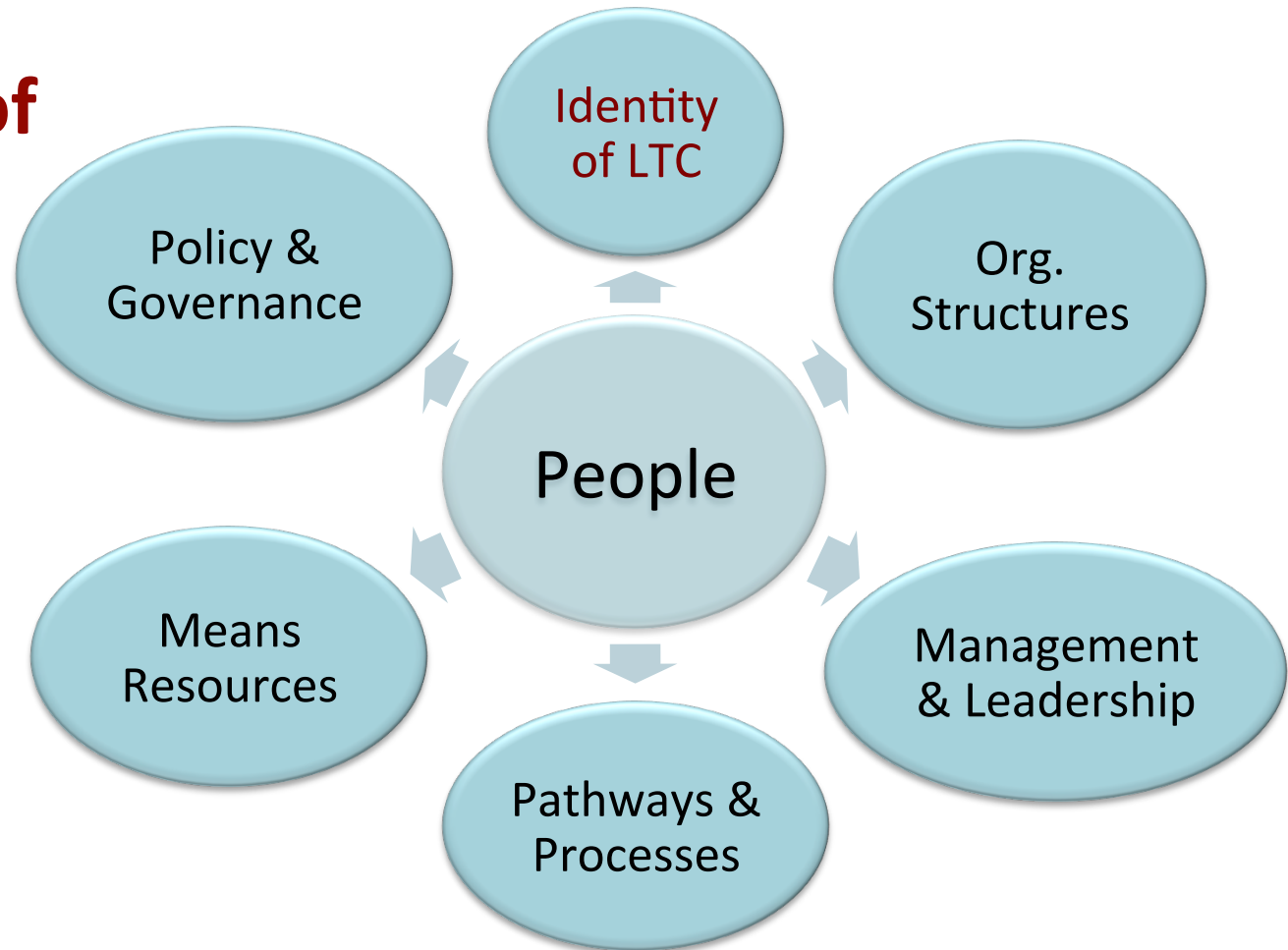
The first leaf of the INTERLINKS flower

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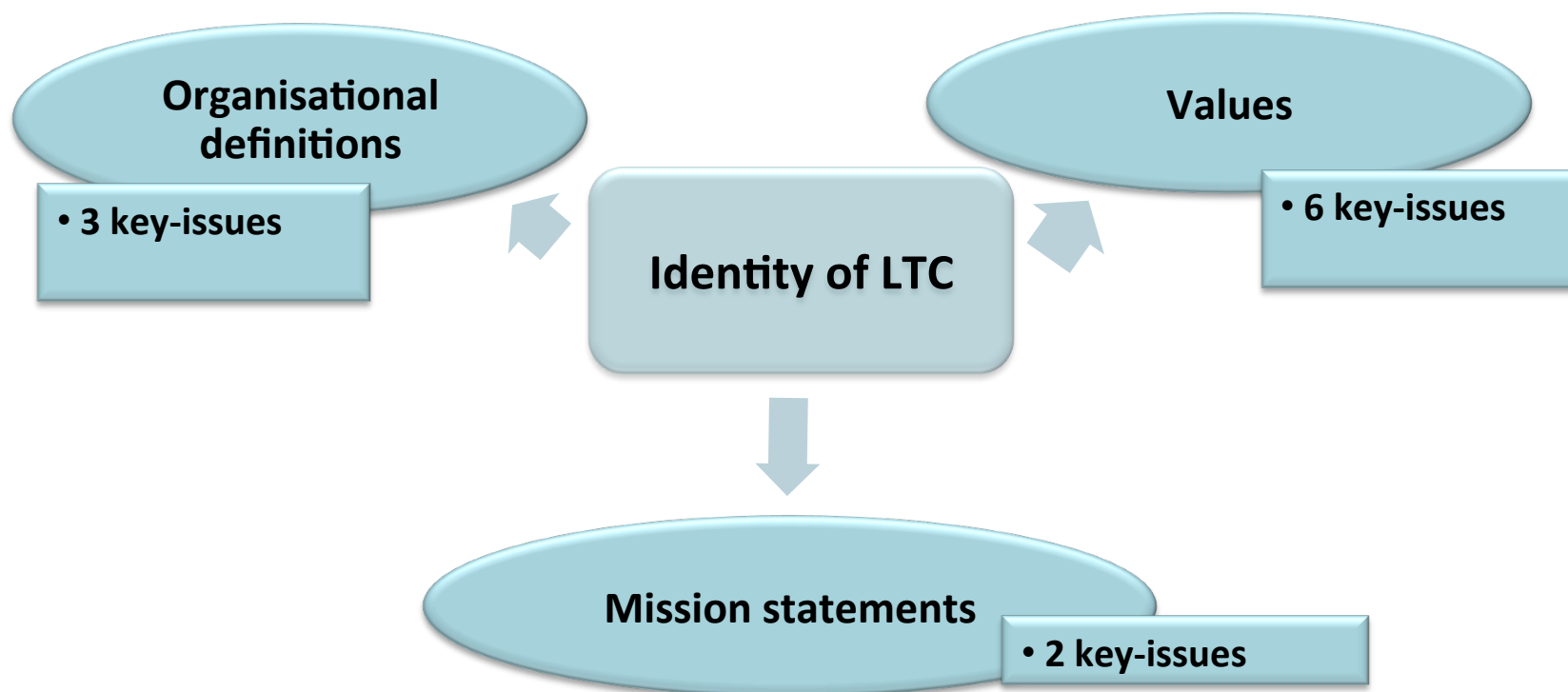


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The Themes of a Long-Term Care System



The theme “Identity” and its sub-themes



Sub-theme 1: Values

- Basic values and rationales in given societies are essential preconditions for understanding political and societal choices in LTC and how LTC is carried out in everyday practice.

Sub-theme 1

Values – 6 key issues

- a) Key principles that characterise LTC
- b) Sets of values that are shaping political, organisational and individual choices on LTC
 - **Example: The Big Care Debate (UK)**
- c) Informal care and/or family ethics in legislative frameworks
 - **Example: Social protection of informal carers (SK)**
- d) Dignity, quality of life and empowerment in policy papers
- e) Values relating to prevention and rehabilitation
- f) Values embracing the diversity of users and carers

Sub-theme 2

Mission statements – 2 key issues

- a) Organisations that explicitly address problems at the interfaces between, formal/informal and health and social care, prevention and rehabilitation or the use of migrant care workers
 - **Promoting the regulation of undeclared work and increasing quality of care work (IT)**
- b) How are problems addressed and what particular factors distinguish an organisation as a LTC organisation

Sub-theme 3

Organisational definitions – 3 key issues

- a) How LTC is defined within or between organisations
- b) How health care providers define their purpose in relation to LTC
 - **Valuable Care (NL)**
- c) How clients are defined and positioned

Template structure

Status
Summary
Key Words

Why implemented?
Which gaps/target
group?

Description
What is it?

4
Template
presentations

IDENTITY

What are the effects?
What evidence?
Transferable?

**Strengths &
Limitations**

Links to docs/website

External Feedback

Identity of LTC: 4 Practice examples

- Jon Glasby, University of Birmingham:
 - Values: **The Big Care Debate** (United Kingdom)
- Kvetoslava Repkova, Institute for Labour and Family Research
 - Values: **Social protection of informal carers** (Slovak Republic)
- Patrizia Di Santo, Studio Come
 - Mission statements: **Promoting the regulation of undeclared work and increasing quality of care work** (Italy)
- Yvonne van Gilse, LOC
 - Organisational definitions: **Valuable Care** (The Netherlands)