

**Improving Access to Palliative Care for Persons with Disabilities:
A Human Rights Perspective
SOCIAL FORUM 2016**

**Palliative care for persons with
intellectual disabilities**



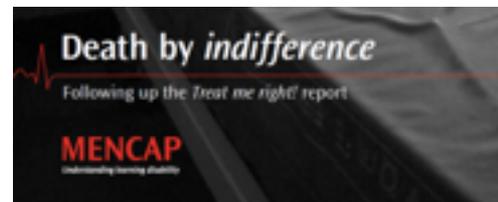
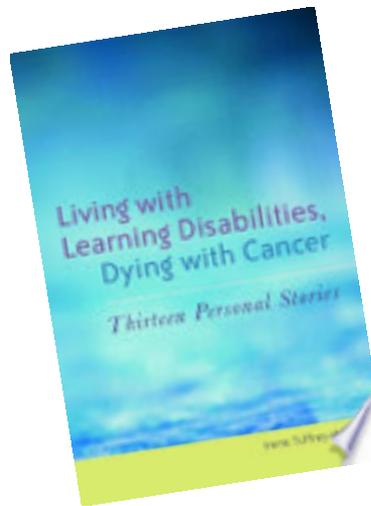
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What is the problem?

People with intellectual disabilities don't have equal access to palliative care

Evidence:

People with ID have low access to health services
Palliative services are not designed for people with



Kevin

Who are they?

- Persons with a reduced ability to understand new or complex information and with reduced ability to cope independently

It covers a wide range of abilities and disabilities, skills and limitations

An estimated 1 - 3 % of the population.

They grow older, and can suffer from life limiting conditions: respiratory diseases, digestive diseases, cancer, epilepsy, dementia,



Why are people with ID at a disadvantage?

Many palliative care needs are **no different** from those of the general population, BUT...

Unique issues and **disadvantages** make it more difficult to meet those needs



- ✓ Communication
- ✓ Insight and understanding
- ✓ Mental capacity and decision making
- ✓ Co-morbidities
- ✓ Relationships
- ✓ Social circumstances
- ✓ Behavioural and psychiatric problems

What did the taskforce do?

EAPC taskforce on people with ID was composed of 12 experts from several European countries :

- Proposing 13 norms
- Evaluation by a panel of 80 experts from 15 European countries
- Collecting examples of good practice



Chair: I. Tuffrey Wijne

Challenges

- Find experts from Eastern and Southern Europe
- Very different settings for people with ID
- Different palliative care services



But:

Large consensus about the norms

Main points of the norms: Human Rights

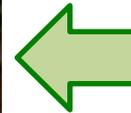
Article 10 - Right to life

Article 25: Health

- (a) Provide persons with disabilities with the quality and standard of health care as provided to other persons, ...
- (b) Provide health services needed because of their disabilities, including **early identification**services designed to minimize and prevent further disabilities, including ...older persons;
- (c)
- (d) Require health professionals to provide care of the same quality ...on the basis of **free and informed consent** by, raising awareness of the human rights, **dignity, autonomy** and **needs** of persons with disabilities through **training** and the promulgation of **ethical standards** for public and private health care;

Main points of the norms: Needs

Developing services:
Education and training
Formal collaboration



Support
Recognising the need of PC
Communication
Involving families, friends and carers
Support for family, friends and carers



Care delivery:
Assessment of total needs: physical, emotional, social and spiritual
Symptom management
End of life decision making
Preparing for death
Bereavement support

A wide network

Family

Friends

Tutor



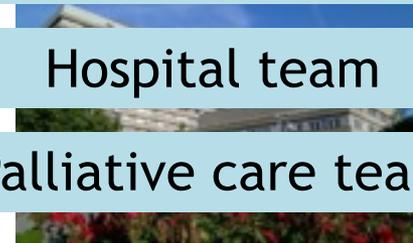
Didier

Specialist oncology

Specialist ID

Hospital team

Palliative care team



Staff working place

Colleagues

Family doctor

Therapist



ID Nurse

Social workers

Roommates

Psychiatrist



What did we learn in Switzerland?

I want to go home

I'm too tired to work, I want to stay in bed

What will happen if daddy dies?



What happens in my belly?

Mummy is ill, I can't go home anymore

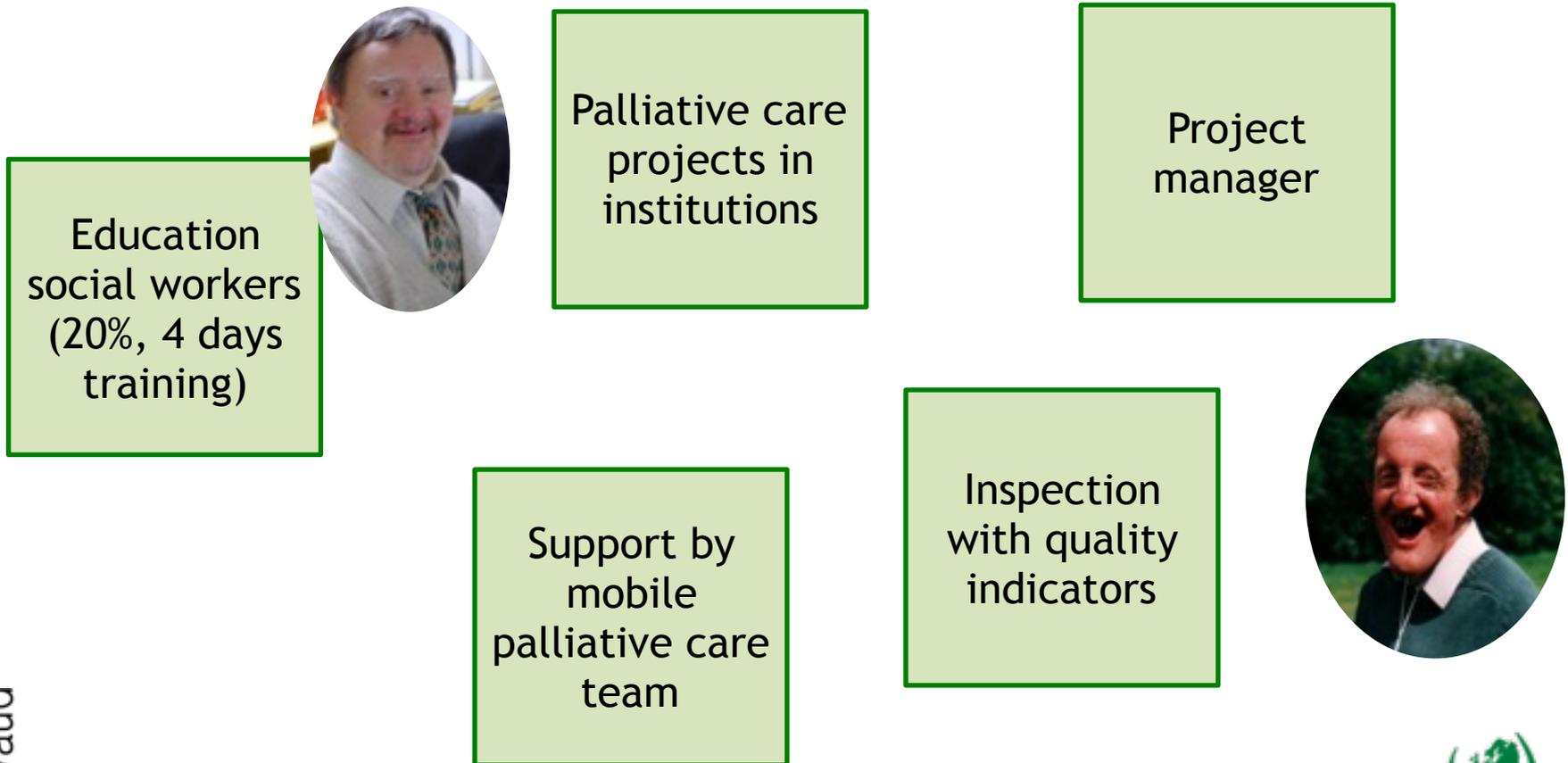
I've have pain everywhere

I want to see the doctor

Listen to the voice of people with ID

What did we do?

A global approach - organised by public health and social department



What did we do - directly for the persons?

Involvement by decision making

Individual support to speak about illness, dying and bereavement



Home take messages

- People with ID also suffer from life limiting conditions
- People with ID also suffer from pain, even if the way to express it can be different (challenging behaviour)
- With suitable communication, most of them can understand a lot and can participate in decision making
- People with ID can also be concerned as beloved ones



Good palliative care services for people with ID, will improve palliative care for other persons with special needs: migrants, physical disabilities, dementia, ...

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About the norms:
www.eapcnet.eu



More information about palliative care and ID:
www.pcpld.org

Thank you for your attention