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V Congrés
del Tercer
Sector Social

Barcelona

V Congrés del Tercer Sector Social

Créixer socialment



Taula d'entitats
del Tercer Sector Social
de Catalunya

The Right to Live in the Community

+ equitat

+ solidaritat

+ sostenibilitat

Peter Lambreghts
ENIL Senior Officer





Who is Peter Lambreghts?



- Expert by experience
- Research & policy
- Belgium & Europe
- Disability & human rights activist
- Peer counsellor & trainer
- Lectures & Publications
- Family man



What is ENIL?

- The European Network on Independent Living
- European wide network of disabled people
- Forum for independent living organisations and our non-disabled allies
- A cross-disability organisation
- Start in Strasbourg 1989 with about 80 persons from 20 countries
- Freedom Drive / Campaigns / Youth
- Find out more on www.enil.eu







Independent Living ???



- No one is entirely independent , but everyone has the (human) right to an independent life. (UN Convention on the Rights of people with disabilities)
- Yet we do not find it peculiar, even rather normal that disabled people are dependent on others (family, health professionals , volunteers).
=> Dependency culture towards disabled people
- <http://www.independentliving.org/docs7/ratzka20071022.html>



“Independent Living is having the same range of options and the same degree of self-determination that people without a disability take for granted.”

<http://www.enil.eu/il-definitions/>



Dr. Adolf Ratzka



Independent Living: the beginning





Independent Living: how it started

- It started from disabled people themselves.
- In the USA , in the 1960s and 1970s.
- Emancipation movement as a reaction to the charity- and medical model.
- Independent Living as a concept and a philosophy based on freedom of choice , self-determination , participation and inclusion.
- Development of the concept of personal assistance (PA) as an alternative to care and institutionalization.
- Successful 'contagion' from disabled person to disabled person.
Importance of peer support and role models
- Advocacy and empowerment through CILs (Centres for Independent living)



Independent Living: how it continued

- After the 1970s: IL comes to Europe and goes global, again it 'spreads' from peer to peer.
- IL gives the intellectual and ideological basis for the UN Convention on the Rights of Persons with Disabilities (UN CRPD).
- In addition to building a basis for social and political action IL also forms the basis for Disability Studies. Disabled people as a researcher and / or in co-production with academics.
- Paradigm shift to social and human rights model.
- Increasing number of 'IL good practice examples'. Small pilot projects as well as generalized approach.
- Increasing emphasis on IL for all disabled (including intellectual, multiple and psycho-social disabilities) and in all areas of life.



Convention on the Rights of Persons with Disabilities (CRPD)

- Adopted by the United Nations in 2006, came into force in 2008
- Specifies how general human rights (Universal Declaration of Human Rights , 1948) can be equally enjoyed by disabled people.
- Paradigm shift from default approach (medical model) to the human rights approach (social model)

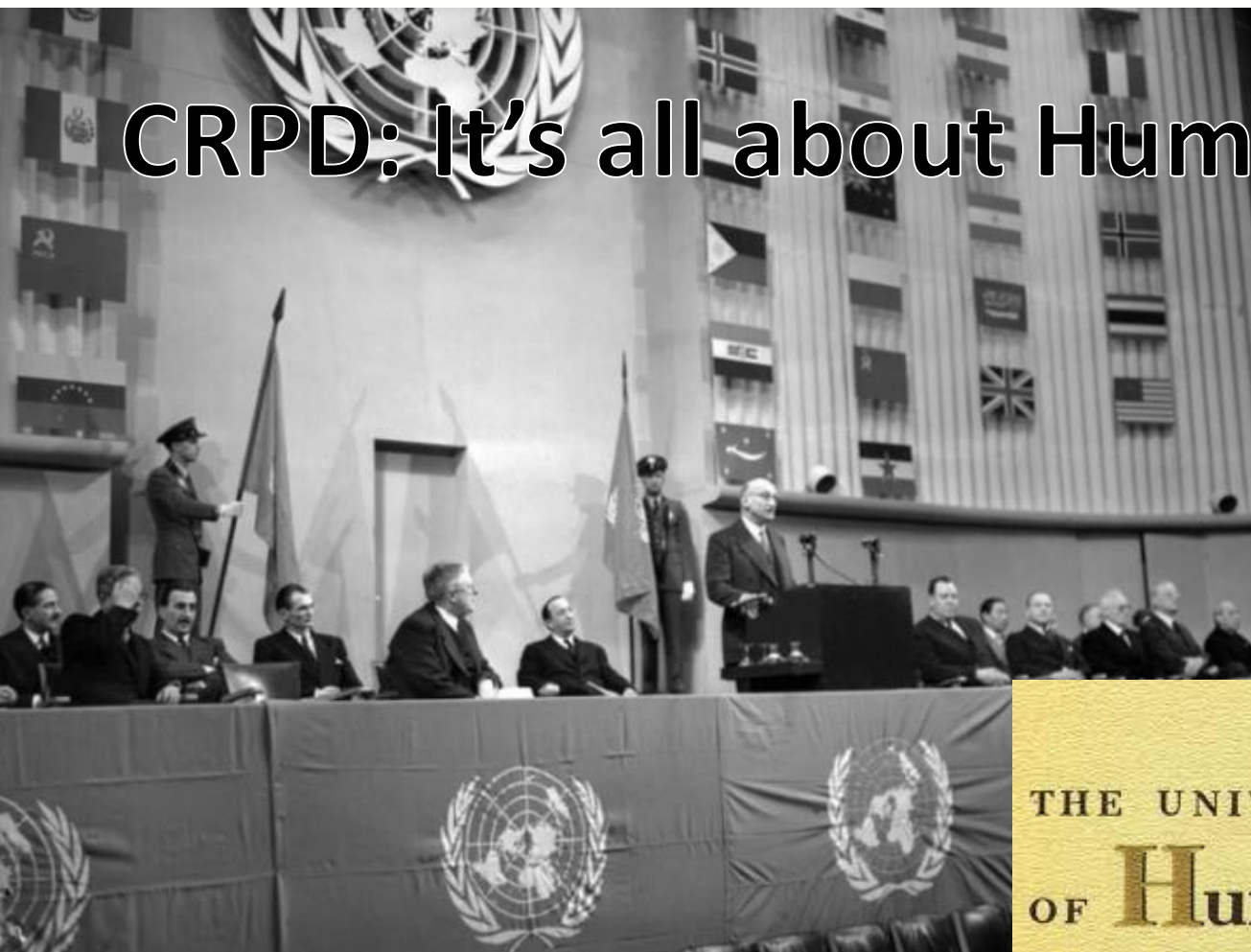


Convention on the Rights of Persons with Disabilities (CRPD) II

- ‘nothing about us without us’ principle.
(artikels 3.c / 4.3 / 33.3 / 29)
- First human rights treaty that provides structures to ensure implementation (Article 33) state actors with coordination mechanism, focal point / independent mechanism / Civil Society Organisations



CRPD: It's all about Human Rights!



THE UNIVERSAL DECLARATION
OF **Human Rights**



- Article 19 – Independent living and support services/Personal Assistance
- Article 9 - Accessibility
- Article 12 – Legal capacity
- Article 14 - Liberty and security
- Article 20 – Freedom of movement
- Article 24 - Inclusive education
- Article 27 – Employment

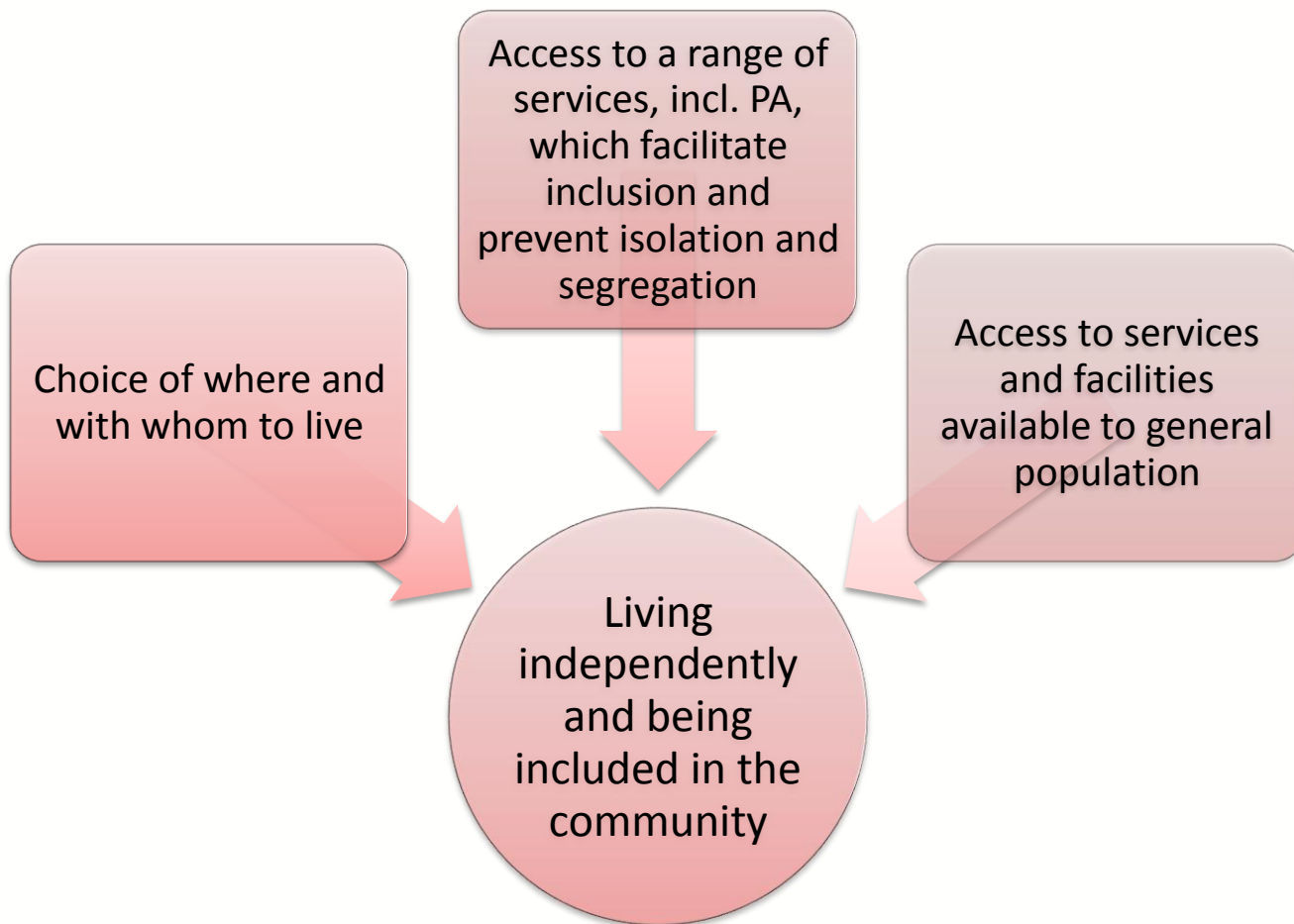
Article 19 - Living independently and being included in the community

States Parties to the present Convention recognize the **equal right** of all persons with disabilities **to live in the community, with choices equal to others**, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their **full inclusion and participation in the community**, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are **not obliged to live in a particular living arrangement**;
- b) Persons with disabilities have **access to a range of** in-home, residential and other **community support services**, including **personal assistance** necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community **services and facilities for the general population are available on an equal basis to persons with disabilities** and are responsive to their needs.



article 19 of the UN CRPD





Deinstitutionalisation in Europe

“Though governments increasingly recognise the inevitability of deinstitutionalisation, there is less clarity with regard to the mechanisms that replace institutionalisation and what would constitute a human rights-based response.”

COE Human Rights Commissioner, 2012



The EEG (European Expert Group on the transition from institutional to community-based support)

Broad coalition of stakeholders representing people with support needs, including:

- children
- people with disabilities
- people with mental health problems
- families
- homeless people; as well as:
- non-profit service providers and public authorities
- intergovernmental organisations (UNICEF and OHCHR)

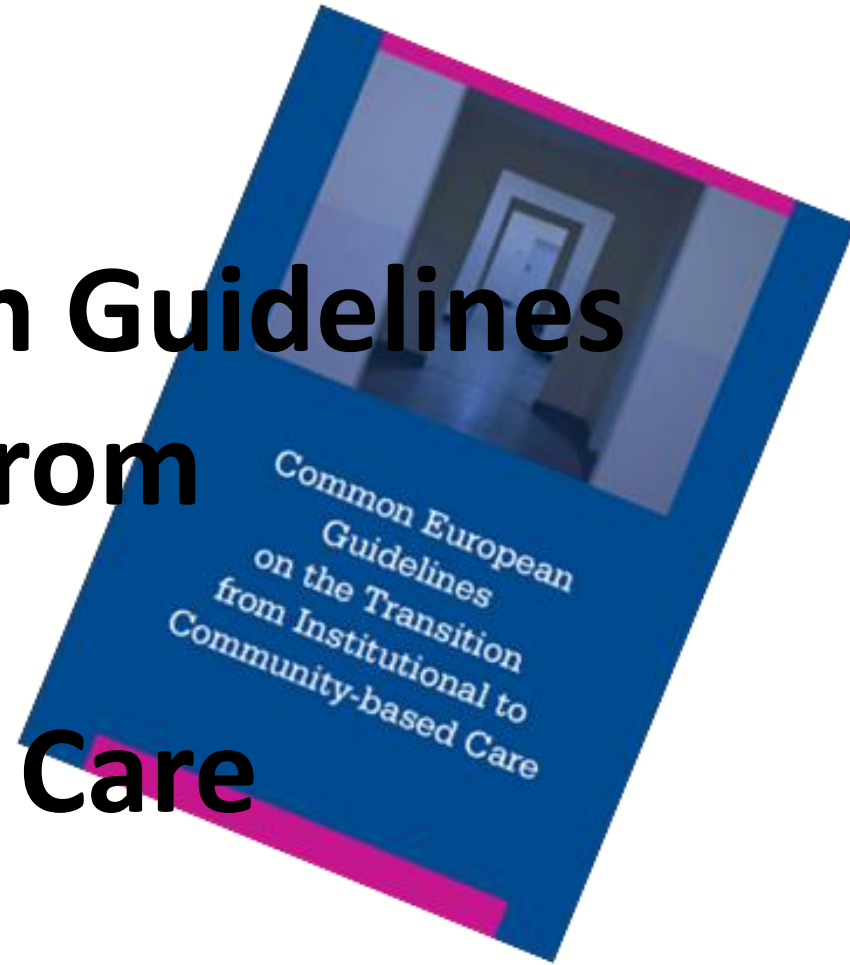
<https://deinstitutionalisation.com/>



Guidelines + toolkit in 17 languages



Common European Guidelines on the Transition from Institutional to Community-based Care





The EEG work:

- Guidelines + toolkit
- Internal meetings, different task forces and open meetings with EC
- Country events/seminars (ESIF => DI)
- Informal advisory body in relation to institutional care reform
- Training on DI to EU officials
- European events (e.g. EU parliament hearings)
- Lobby actions on EU level and in the Member States



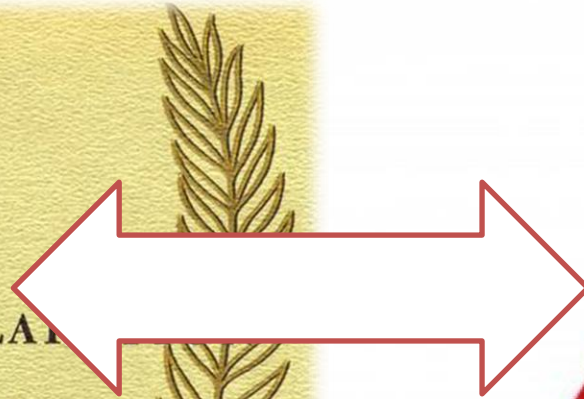
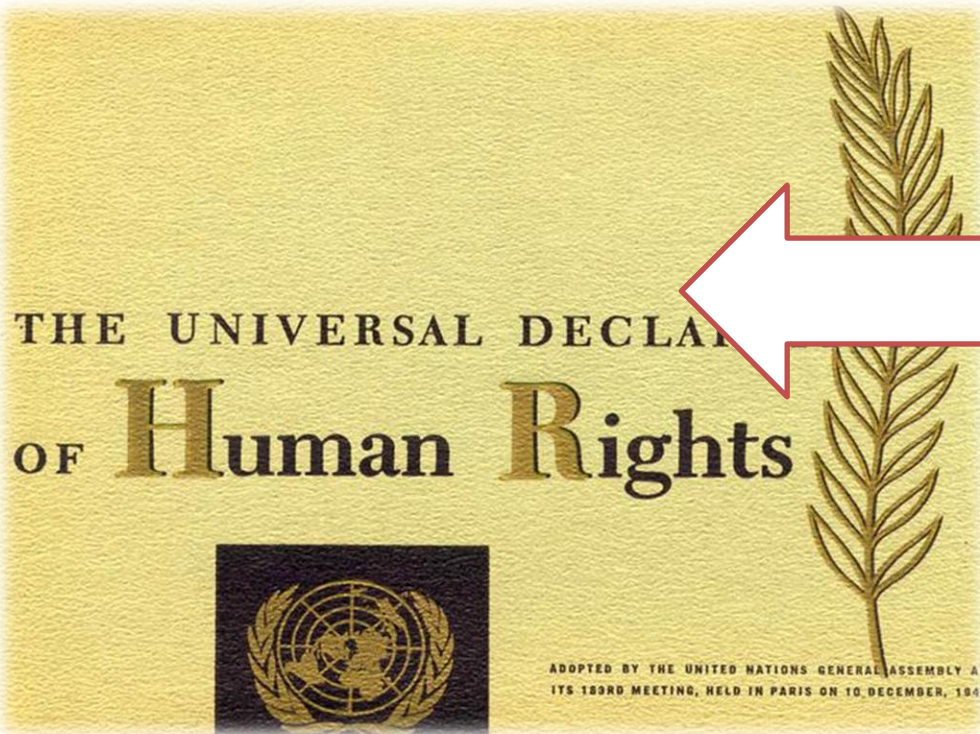
Today's reality

- Institutions – building and renovation
- Lack of community services
- Lack of accessible housing
- Lack of personal assistance
- Lack of involvement of disabled people / lack of co-production (http://www.enil.eu/wp-content/uploads/2014/05/FAQ_Co-production.pdf)
- Attitudes – disabled people seen as burden or pitiful, no potential, paternalistic approach, ...

Growing gap between CRPD 'promise' and reality in the lives of disabled people

European Foundation Centre study entitled: "Assessing the impact of European governments' austerity plans on the rights of people with disabilities".

<http://www.enil.eu/news/european-foundation-center-launches-study/>





key principles for inclusion of disabled people in the community

- Social model on disability
- UN CRPD article 19 (*Personal Assistance!*)
- Empowerment & emancipation
- Peer to peer counseling / peer support / importance of role models
- Co-production of support services & policy
- Community building
- Reallocation of public investment, from care in kind towards direct payments



It's all about (em)power(ment)

Direct payments = the ultimate tool and win-win for all.



If You're
NOT Part of the
Solution You're
Part of the **Problem.**

Thank you for your attention
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Amb el suport de:

