

Real inclusion in the community: The Zero Project and Independent Living



International Conference: *Tuttavia...liberi di scegliere!*

San Marino, December 3rd, 2014

Presented by: Ingrid Heindorf, Zero Project

What is the Zero Project?

- A project of civil society, initiated by the **Essl Foundation** (Austria), run in partnership with the **World Future Council** (Germany) and the **European Foundation Centre** (Belgium), started in 2011
- **Its Mission** is A World without Barriers, supporting the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD), by:
- 1. Research and selection of most outstanding **Best Practice** examples that effectively improved the situation of persons with disabilities: **Innovative Practices and Innovative Policies**
- 2. Evaluation of the state of implementation of the UN CRPD worldwide with **Social Indicators**
- Our research is based on the **Zero Project Network** of disability experts: More than 3,000 of them have contributed since 2011.
- Communication: Zero Project **Report, Website** and **Conference**, Side Events at national and international conferences, and Social Media.
- **Annual topics**: 2013 - Employment; 2014 - Accessibility; 2015 - Independent Living and Political Participation; 2016 – Education.

Zero Project



Thematic Partners 2014/15:

- IDA – International Disability Alliance
- DPI - Disabled Peoples International
- **ILI - Independent Living Institute**
- GAATES - Global Alliance on Accessible Technologies and Environments
- RIADIS - Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families
- HRW - Human Rights Watch
- **ENIL - European Network of Independent Living**
- **ECCL - European Coalition for Community Living**
- **EEG - European Expert Group on the Transition from Institutional to Community-based Care**
- AER - Assembly of European Regions
- IFES - International Foundation for Electoral Systems
- ITU - International Telecommunications Union
- Light for the World Austria
- Inclusion Austria

Topic 2014/15: Independent Living

In spring 2014, our call for nominations asked the global Zero Project network of disability experts - composed of about 3,000 people - to submit innovative practices and policies that have clearly and measurably improved Independent Living of persons with any kind of disability.

- The Call was available in ten languages, including all five official UN languages but also English plain language for example.
- The Call included the [definitions](#) of **Independent Living** and **Community living** elaborated by our partner the European Network for Independent Living, on the basis of Article 19 of the UN Convention on the Rights of Persons with Disabilities.

Topic 2014/15: Independent Living

The Zero Project was looking especially for outstanding practices and policies that addressed an individual's self-determination* and thus the following subcategories of Independent Living:

Choices and decision-making

- Equal recognition before the law,
- Choice of living arrangements,
- De-institutionalization, etc.

Community-based services

- Focus on personal assistance services for self-care, household care, mobility, leisure and community participation, assistance animals;
- Independent housing, community living arrangements and housing adaptation;
- Communication support;
- Information and advice services, including professional, peer support, advocacy and supported decision-making;
- Quality, coordination and innovation of service delivery, etc.

Assistive devices

- Technical aids, information platforms, innovative devices, ambient assistive living, etc.

Please note that practices and policies linked to **employment and **accessibility** had been already covered in previous years.*

Topic 2014/15: Independent Living

By August 14th we received **230 nominations** from **more than 75 countries** from around the world – from Australia to Zimbabwe!!

The Zero Project research and final selection process was finished by the end of September 2014 and produced:

- **11 Innovative Policies** &
- **45 Innovative Practices.**

Five Innovative Policies 2015 concerning Independent Living

- AUSTRIA: Peer Counseling as a social profession in Upper Austria
- SWEDEN: Right to Personal Assistance & BELGIUM: Flanders' Personal Assistance Budget
- LUXEMBOURG: Creation and funding of a national disability information and meeting center
- SWEDEN: A nationwide system of Personal Ombudsmen

AUSTRIA: Peer Counseling as a social profession in Upper Austria

Acknowledging that Peer Counseling is crucial to empower persons with disabilities, Upper Austria established, for the first time worldwide, Peer Counseling as a social profession, which values the experience of physical, psychosocial and intellectual disability as a fundamental quality.



- Since 2009, disability-specific qualification courses (psychosocial, physical and intellectual) certified more than 70 professionals.
- In 2014, 76 Peer Counselors are offering up to 1,320 hours per week, tailored to type of disability.
- They are active at many levels and in different organisations.

SWEDEN: Right to Personal Assistance

Many countries are still far from the goal of enabling persons with extensive disabilities to choose the support that best suits their needs. Sweden stands out in offering citizens a wide range of alternatives and control over the services they need to live independently in the community.



- In 2013, 19 500 people used personal assistance.
- Ca. 90 % live in ordinary homes, alone or together with a partner, a housemate, or parents.
- The system of cash payments created a competitive market for personal assistance consisting of 230 local governments and over 800 private entities.

LUXEMBOURG: Creation and funding of a national disability information and meeting center

As policies targeting people with disabilities are often not coordinated, people have difficulties to find their ways through bureaucracy. A national disability information center is a classic win-win solution: It assists people with their administrative procedures and helps policymakers to shape inclusive policies.



- In 2013, 2,271 persons asked for advice. 597 used the legal information service.
- Info-Handicap has now 55 member organizations.
- It has developed guidance books and has influenced laws and practices in Luxembourg and beyond.
- Since 2005, it held the competition “A municipality for everybody”.

SWEDEN: A nationwide system of Personal Ombudsmen

Guardianship, hospitalization, institutionalization, powerlessness, isolation, drug addiction, homelessness, suicide and violence: A Personal Ombudsman can help to prevent this and be a true change maker in the lives of many persons.



- In 2014, 245 municipalities - 84 % of all - have a PO.
- And 310 PO, employed in over 110 businesses, provided support to more than 6,000 individuals.
- Support by a PO shows positive response rates as it reduces guardianship, isolation and homelessness.
- Positive impact on economy and employment.

Examples of Innovative Practices 2015 concerning Independent Living

- NORWAY: Building a business: personal assistance as a tool for independent living
- UNITED KINGDOM: Disability Rights UK Independent Living Helpline
- GERMANY: Supported Self-directed Personal Assistance (Case Management)
- MOLDOVA: An integrated programme of deinstitutionalisation and developing inclusive education

NORWAY: Building a business: personal assistance as a tool for independent living

Uloba, Independent Living Norway, is a cross-disability organization. Five disabled entrepreneurs founded the organization in 1991 which is organised as a cooperative society owned by its members – the users of personal assistance. Today, Uloba consist of nearly 1,000 work leaders who supervise 6,000 assistants. Uloba is currently Norway's main facilitator of personal assistance. Uloba makes the Independent Living ideology's vision happen in real life.



UNITED KINGDOM: Disability Rights UK Independent Living Helpline

With its helpline Disability Rights UK provides advice on getting direct payments, including information on individual budgets/personalisation, funding from social services in relation to the care needs of the disabled and general advice on employing personal assistants. We provide factsheets, free to download from the DR UK website, on charging for community care, charging for residential accommodation, community care direct payments, complaining about local authority decisions, personalisation and the right to control.



GERMANY: Supported Self-directed Personal Assistance (Case Management)

The project provides case management for disabled people who are employers of personal assistants. It thereby encourages even more people with disabilities to organize their personal assistants themselves (with support). The project is thus addressed to persons with disabilities, who would like to learn more about the responsibility to run a business through which they employ their personal assistants AND to those who need support - for intellectual or other reasons - in running such a business.

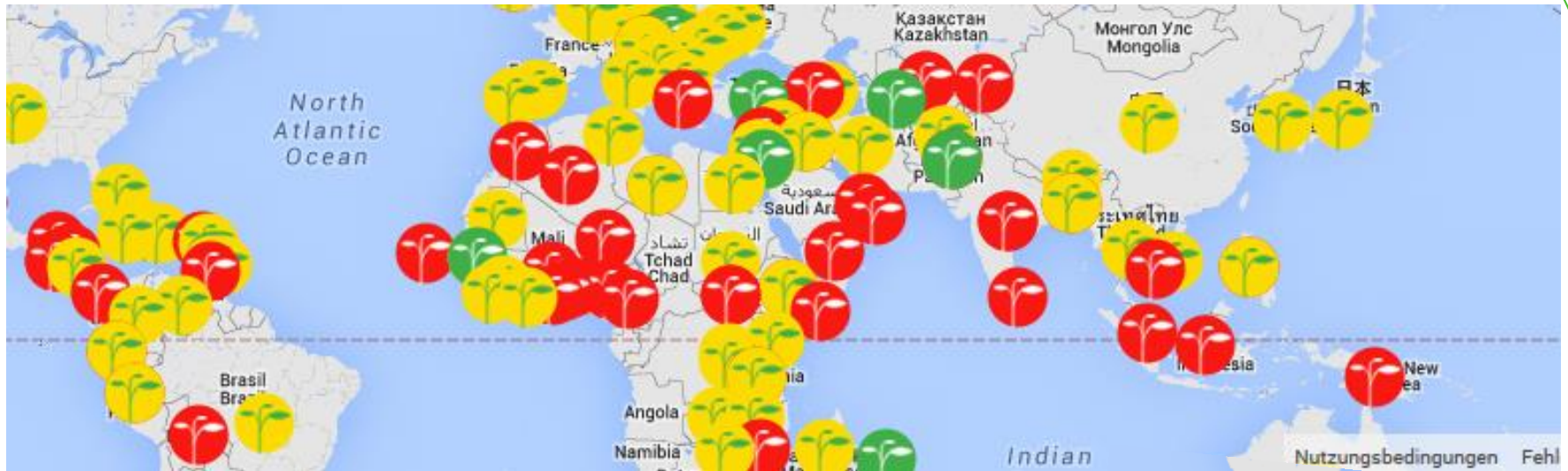


MOLDOVA: An integrated programme of deinstitutionalisation and developing inclusive education

The integrated programme of deinstitutionalization and inclusive education put in place community based social services making it possible for children with disabilities in institutions to go home to their families or be placed in foster care. Simultaneously, it developed inclusive schools to make it possible for children with disabilities to be educated in mainstream schools, alongside their peers. Since, the number of children in institutions has been reduced from 13,000 to less than 4,000 and the number of children with disabilities in inclusive schools has increased from 0 to 4,300.

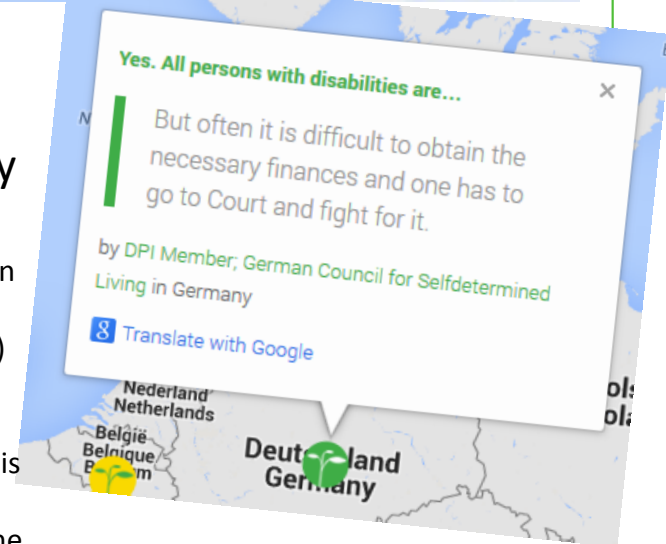


Zero Project Indicators



In 2013, DPI USA for example replied on Indicator 7. Living Independently and being included in the community:
Yes, with qualifications. Such finance, although mandated by law, is either not available to all, or is limited in extent.

People's right to live independently and be included in the community is upheld not only in law (Americans with Disabilities Act) but also by the Supreme Court in an important legal decision, Olmstead. (See <http://www.ada.gov/olmstead/index.htm> for some background.) However, actual translation of this decision into the budgets of individual state governments has been very uneven from one state to another. Some states still only provide support for certain kinds of personal care services via institutions. The effect of this is that people with disabilities in certain parts of the country may need to pay for their personal care support out of their own pockets, or else accept being institutionalized as the only way to receive assistance with tasks such as bathing, eating, etc.



2014/15: Ten Zero Project Indicators on Independent living 1

SUPPORTED DECISION-MAKING ALTERNATIVES:

Are supported decision-making alternatives available to all persons with disabilities?

SAFEGUARDS:

Do appropriate and effective safeguards exist for all processes relating to legal capacity and support in exercising legal capacity?

RIGHT TO MARRIAGE AND HAVE CHILDREN:

Do persons with disabilities have the same rights as others to marry, have children and raise those children?

DATA COLLECTION ON INSTITUTIONS:

Are official statistics published annually covering, at the minimum, the number, age group, gender ethnicity and primary disability for all persons with disabilities living in residential care settings?

ALTERNATIVES TO INSTITUTIONS AND DECISION MAKING:

If forms of residential care exist in your country, are there any alternatives to institutions and do people with disabilities have choice and control over the services they use?

2014/15: Ten Zero Project Indicators on Independent living 2

DE-INSTITUTIONALISATION PROCESSES:

If forms of residential care exist in your country, is the number of persons with disabilities living in institutional care decreasing due to the increased availability of quality services in the community supported and funded by the state?

PROTECTION AND MONITORING:

Are facilities and programmes designed to serve persons with disabilities effectively monitored by independent authorities?

ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION:

Do measures and safeguards exist to ensure the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing?

AVAILABILITY OF PERSONAL ASSISTANCE SERVICES:

Is personal assistance available in your country?

AVAILABILITY OF ASSISTIVE DEVICES AND TECHNOLOGY:

Is there public funding available to ensure that people with disabilities have access to the necessary assistive devices and technologies?

Thank you very much for your attention!!

And please join our Network!

Website www.zeroproject.org

Facebook www.facebook.com/zeroproject.org

Twitter <https://twitter.com/zeroproject.org>

Youtube www.youtube.com/user/Zeroprojectorg

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