

# 5 minutes after 12

## Time to escape the trap of institutional care

75 years since the Universal Declaration of Human Rights, 50 years since the first scientific research into the problem, 30 years since Czech professionals started critically engaging with it, and yet we are still trapped in the depths of an expert error – institutional care for people who need help and support by others.

- despite the hard work and dedication of parents, non-profit organisations and support from general public that have led to development of quality services allowing people to live in their homes, with their families and leading normal lives;
- despite many service users who have managed to leave institutional care supported by professionals
- despite growing understanding among politicians and public administrators of institutional care as a problem, of their accountability for it, and despite a number of programmes designed to deal with it;
- despite ratification of the Convention on the Rights of Persons with Disabilities and other disability rights legislation by the Czech Republic;

**tens of thousands of people in this country still live in institutional care.** And any of us may one day become one of them.

On the one hand, community-based services have been set up in the last twenty years. On the other hand, tens of thousands of people live in hundreds of institutional care facilities, and their numbers are increasing.

On the one hand, people are supported to leave institutional care and to live normal lives with support in the community. On the other hand, institutional care facilities have undergone expensive maintenance work and modernisation, and even new facilities have been set up.

On the one hand, declarations, policies and strategy documents speak of supporting independent living in the community. On the other hand, legal, organisational and financial systems and mechanisms favour institutional care.

**We have set out towards normal life, yet one leg is still trapped in institutionalism.** The longer we remain there, the more frustration and dissatisfaction is caused because we already know that the world without institutional care is possible.

We wish for a country where as citizens we respect one another without prejudice and stereotypes; where civilisation is measured by care provided for the weak; where we can look into the mirror without fear because we know that we have not left them behind the walls of institutions.

We wish for a country where people's home is with their family, near their friends, schools, work, in an area they know; where we are not sent far away, behind the walls of institution, when we need help and support.

We wish for a country where we do not need to fear what happens when we cannot cope with care for our family members; where we know that support is

**Institutional care** takes place **behind walls** of large residential facilities where people live **separated from normal lives** and excluded from having a stake in everyday life of society. People in institutional care **don't have their own housing**, and live surrounded only by paid workers and other people with similar difficulties. **People in institutions are subjected to regimes and rules.** They cannot develop independence and their own will. **Institutional environment leads to giving up on normal life;** it is a source of restricting and contravening the rights of people who live in institutions.

**11 000 children** in residential institutions, diagnostic facilities and institutional social care

**15 000 adults with disabilities** in institutional social care

**9 000 people with mental health problems** in psychiatric facilities

**53 000 elderly** in residential services and long-term care facilities

available to allow them living where they are used to; where our caring efforts will not end in vain when people are sent behind the walls of institutional facility.

We wish for a country where we can use and develop professional skills to support service users living independently in the community; where we do not need to fight against legal, organisational and financial barriers that keep people in institutional care.

We wish for a country where we are trained to recognise risks of institutional care that threaten users and practitioners alike, and where we know how to leave institutions.

We wish for a country where politicians and public administrators have created legal, institutional and financial conditions that support independent living in the community; where the law does not favour institutional care and where majority of public funds does not help maintaining institutional facilities.

## **World without Institutions Initiative**

We accept that as a society we do not do enough to meet the rights and needs of people with disabilities. We are dedicated to making a change so that we can live in a world without institutions as soon as possible.

We shall connect those wishing to leave institutional care and those wishing develop support in the community with those already working towards it so that they can share their experiences, and inspire and empower each other.

We shall draw attention to how institutions affect lives. We shall tell stories of people in institutions until they all have left. That way our society shall be reminded how we all are limited and impoverished by segregating some of us in institutions.

We shall demand that political representatives and public organisations act in accordance with the constitution, the Charter of Fundamental Rights and Freedoms, and the Convention on the Rights of Persons with Disabilities to ensure protection of rights and support for independent living for all of us.

**Time to escape the trap of institutional care has come long ago.**

**We appeal to politicians, public officials and health and social care professionals to make sure that all citizens are provided with care in their communities in place of institutional care.**

**We invite all who aim for deinstitutionalisation to join this appeal and to share their experiences, knowledge and powers for the common life of people in the community.**

in the Czech Republic, on the International Day of Human Rights (10 December 2013)

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**Appeal to deinstitutionalisation is supported by**

Institutional care facilities, and people in them, have statutorily a better standing than community care services.

Majority of personal social services funding goes to institutional care.

EU funds are used for building new institutional facilities although it contravenes EU policy.

States Parties shall take measures to ensure 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; a

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, Convention on the Rights of Persons with Disabilities

**Deinstitutionalisation** means transformation of institutional care into community-based care. People using public services **gain freedom to chose the place of living**, chance to use local services; **have usual social roles** (e.g. daughter/son, partner, friend, pupil, neighbour...); **live ordinary life patterns** (e.g. go to school or work).