



Joint Declaration: Developing the Support Services of Tomorrow

Co-produced between:



With the support of



With the financial support of



The European Union Programme for Employment and Social Innovation "EaSI" (2014-2020). The information contained in this publication does not necessarily reflect the official position of the European Commission.

PURPOSE OF THE JOINT DECLARATION

This Joint Declaration aims at providing a common understanding between signatories on the direction support services should take to enable full inclusion. It also lays the ground for future discussions and cooperation between signatories towards this end. The development of this Declaration has been coordinated by Mr Thomas Bignal, EASPD. It has been co-produced with Ms Magdi BIRTHA (COFACE), Mr Luk Zelderloo, Ms Sabrina Ferraina (EASPD), Ms Laura Marchetti, Ms Simona Giarratano (EDF), Mr Frank Sioen, Mr Peter Lambreghts (ENIL), Ms Aleksandra Ivankovic, Mr Milan Svarepa (Inclusion Europe) and Ms Ailbhe Finn (Mental Health Europe).

In memory of Mr Peter Lambreghts, who was Senior Policy Officer at the European Network on Independent Living when this Declaration was being developed. Peter's contribution to the development of high quality support services was both significant and exemplary.

STATE OF PLAY

The UN Convention on the Rights of Persons with Disabilities (CRPD) is the **definitive international human rights treaty setting out the rights of persons with disabilities**. The CRPD introduced a holistic and integrated human rights-based approach to address civil, political, economic, social and cultural barriers faced by persons with disabilities. The CRPD does not introduce new rights for persons with disabilities as its aim is to apply existing human rights to all persons with disabilities and close the implementation gap that prevented them from enjoying these rights on an equal basis with others. The Convention manifests the **human rights model of disability** and calls for the removal of all socially constructed barriers which are the main cause of the social exclusion of persons with disabilities. Society (including public authorities) is therefore required to put in place **structures that enable the full participation of persons with disabilities** in society and measures that will create inclusive communities.

Individualised support, person-centred planning, co-produced services and the empowerment of individuals and their families are elements required to be part not only of the outcomes of policies, but should be carefully built into all processes and policy instruments.

Accessibility is also a fundamental issue; meaning

that policies and legislation must identify and eliminate obstacles and barriers to participation and ensure that persons with disabilities can access the environment, transportation, public facilities and services, information and communications technologies.

The EU and all its Member States have signed the UN CRPD. At the time of writing, 27 of the Member States and the European Union itself have ratified the Convention. Ratification is legally binding and obliges state parties to include its principles in existing and future law and policy developments in all areas of life. The UN CRPD also shows the way in which support and care should be provided to ensure independent and community living and to move away from a medical model of care towards a human rights-based approach, where **individuals are supported to become active citizens in their communities** and where support is tailored to individual needs and aspirations. The main problem with the medical model is that it provides only limited freedom of choice and responsibilities for users and their families and sees impairment as an individual burden, rather than a socially constructed barrier. **In light of the Convention it is time to move from a protective approach towards an empowerment-oriented attitude.**

This must change through three main steps, which

should all include the involvement and consultation of persons with disabilities and their representative organisations:

- ⇒ Aligning all legislation with the UN CRPD obligations;
- ⇒ Ensuring that mainstream services fully include persons with disabilities; whilst setting up

appropriate support schemes and services and readapting existing ones, according to the international standards set by the Convention;

- ⇒ Raising awareness in society on the rights of persons with disabilities in order to promote their full inclusion and participation in society.



ROLE OF SUPPORT IN IMPLEMENTING UN CRPD

The UN CRPD should be understood through its general principles – as per Article 3: autonomy, independence, non-discrimination, participation and inclusion, equality of opportunity, accessibility, respect for diversity, equality between men and women and respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

There are four articles in which support plays a more relevant role in contributing to the principles of the UN Convention:

- Article 12: Equal recognition before the law
- Article 19: Living Independently and being included in the community
- Article 24: Education
- Article 27: Work and Employment

These articles set general direction to the way in which support should be carried out in line with international human rights standards; for which the fulfillment should be the objective of all society. The articles should be read in line with the principles of the CRPD as a whole.

It is important to note that a **crucial factor for the development of a truly inclusive society is to change the mindset of the general population – and its political and civil representatives- towards the principles of the UN Convention.** This being said, high quality personalised and co-produced assistance services – in line with the UN CRPD- are essential to enable persons with disabilities and their families to exercise their rights.

It is necessary to recognise that many social service providers are already providing human

rights-based models of support, whilst others are making important steps to provide such support. However, **more needs to be done to ensure that all social service providers are in line with the standards set out in the UN CRPD.**

ARTICLE 12: EQUAL RECOGNITION BEFORE THE LAW

Article 12 of the UN Convention obliges states parties to ensure that **persons with disabilities are recognised as persons before the law to enjoy legal capacity on an equal basis with others in all aspects of life.** State parties must also take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity and to provide appropriate and effective safeguards against abuse. Last but not least, it obliges countries to ensure the equal right to own and inherit property, to control financial affairs and to have equal access to bank loans, credit and mortgages.

Under article 12, the transition away from a system based on a “substituted decision-maker” (guardian) towards supported decision-making regimes must include various support options that are based on the person’s will and preferences and provide protection for all rights, including those related to autonomy and to freedom from abuse or ill-treatment. Supported decision-making refers to a decision made by a person, with as much formal support, or informal as the individual needs.

ARTICLE 19: LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY

Article 19 of the UN Convention states that **persons with disabilities should live where they wish and with whom they wish in order to live independently and be included in the community.** Furthermore, they shall have access to a range of in-home, residential and other community support services including personal assistance. Persons with disabilities should enjoy community life and its opportunities on an equal basis with others and they should not be subject to isolation or segregation.

Under article 19, any support must strive to help enable a person's right to live independently according to his or her own choices and decisions. This means that the support and care must be provided for the individual in his/her home setting and respond to the individual's needs, will and preferences. Co-production² is a crucial working method to ensure that support services are developed and run in manner in line with the UN CRPD. This is only possible through the transition from institutional to community-based care, driven by a respect for human dignity, equality and rights. It involves promoting access to mainstream services for persons with disabilities, such as housing, healthcare, education, employment, culture and leisure, without losing out on the quality of support and care needed. Relevant support and recognition of family careers is indispensable to ensure quality family life and to prevent institutionalisation, especially from the early years. Support and recognition must also contribute to the individual choice and empowerment of the individuals. Adults with disability must have the choice between family support and other community based services, or a combination of the two.

ARTICLE 24: EDUCATION

Article 24 of the UN Convention obliges state parties to **ensure equal access to inclusive primary, secondary and higher education, vocational training, adult education and lifelong learning.** Learners with support needs are to receive support measures conducive to full

participation in inclusive education. Education of persons with disabilities must foster full participation in society, the sense of dignity and self-worth and the development of personality, abilities and creativity.

Under article 24, support in inclusive education is about adapting the learning environment and approaches to the individual needs of the student or pupil. The front row of inclusive learning environments remain the staff, such as teachers, counselors, assistants and headmasters; who must therefore receive adequate education and training. Adequate funding should be made available to develop inclusive learning environments for all pupils and students. Successful partnership between the learning environment and families and careers is essential for good educational outcomes for all children.

ARTICLE 27: WORK & EMPLOYMENT

Article 27 of the UN CRPD obliges state parties to **ensure that persons with disabilities have equal rights to work and to gain a living.** Ensuring equal access for persons with disabilities to the open labour market is to be a priority in this regard.

Under article 27, support measures must help to overcome structural and functional barriers to the labour market, including issues linked to stigma. These should be based on sustainable legislative and financial frameworks that ensure that long-term support and income needs can be met. The support for both the person with a disability and the employer may include vocation and educational training, reasonable accommodation, accessible services, technical guidance, the possibility to use personal assistance for employment, subsidies for employers, among others. Other anti-discrimination measures can also play a positive role to ensure equal access to the labour market for employment of persons with disabilities.

¹ References to residential services should be taken to mean services which Support community inclusion and are not institutional in line with Art 19 of the CRPD.

² Co-production should be understood here as the definition agreed by all signatories and available in annex.

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TERMS OF COOPERATION

Implementing the transition towards a human rights approach to services requires cooperation between different stakeholders, with the full involvement of organisations representing persons with disabilities, is therefore necessary. There is a fine balance between improving and developing sustainable, individualised and empowering models of support, whilst also ensuring that support systems remain available for all people regardless of the level of support needed.

The UN CRPD presents a clear vision on how support for persons with disabilities and their families should be provided. Careful planning as a result is required to avoid unintended harmful consequences and to ensure that the outcomes are fully in line with the UN Convention and the preferences of persons with disability. The transition to community-based care and support models in Europe is also affected by broader debates; such as the impact of the economic crisis, the role of the State in the financing, regulation and provision of services, an ageing population, growing demand for support and care, difficulties in recruiting and retaining staff, adapting to the digital age and technologies, gender inequalities, migration flows, high levels of unemployment, among others.

The objective of this cooperation is fourfold:

- ⇒ Improve trust between stakeholders and understanding of each other's position;

- ⇒ Find common solutions on how to strengthen a human rights-based approach in European policies and processes;
- ⇒ Develop guidelines and exchange promising practices on support models in line with the CRPD.
- ⇒ Strengthen cooperation with mainstream stakeholders and involve them in discussions and processes.

In order to positively contribute to building a more inclusive society through high quality support systems, signatories commit their willingness to cooperate for a minimum of two years and to the extent of somewhat limited resources to discuss, exchange views and work together on how support should be developed and produced to realise a society where all people are free to choose their jobs, education and home. Over the two years, several meetings will be organised to discuss the development of common position papers, research activities and project on the development of support in the future. Following these two years, a meeting will be organised to review developments and work between cooperating organisations.

This Joint Declaration will serve as the first basis for discussions. Terms of cooperation will be developed, discussed and reviewed throughout the process of the cooperation.

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SIGNATORIES

Signatories subscribe and commit to all principles, values and provisions of the UN Convention on the Rights of Persons with Disabilities. Signatories also subscribe and commit to the content of this Joint Declaration.

Signed in Brussels, on 4th December 2018.



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