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**REPORT**

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# EASPD CONTRIBUTION TO THE

# DRAFT GENERAL COMMENT ON ARTICLE 19 UNCRPD

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# Executive Summary

This report aims at giving EASPD’s inputs to the CRPD Committee Draft General Comment on Article 19 “Living independently and being included in the community”.

EASPD presents the role of support services in the development and set-up of community-based living solutions for persons with disabilities in the European context, having around 150 member-organisation within its organisation and representing in total 15.000 social and support providers.

Support services play a key role in the implementation of Article 19; it is therefore essential to have in place strong methodologies to ensure the design, development and delivery of the service is tailored to the individual needs and wishes. EASPD believes one of the ways forward in this regard is represented by the implementation of co-production methodologies whereby users, support services and all relevant stakeholders are meaningfully involved in a cooperative way, leading to outcomes that are co-produced.

# 1. Introduction

**Who is EASPD**

[EASPD](http://www.easpd.eu) (European Association of Service providers for Persons with Disabilities) is a European NGO network representing 15,000 social and health support provider organisations across Europe and across disabilities. Our objective is to promote equal opportunities for people with disabilities through effective and high-quality service systems. We work towards ensuring the full implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and we are accredited to the Conference of States Parties to the CRPD.

EASPD is fully committed to the implementation of the Convention on the Rights of Persons with Disabilities and the promotion of deinstitutionalisation accompanied by the development and set up of community-based services is among the core objectives of EASPD.

Part of the work of EASPD related to implementation of Article 19 is done through the “European Expert Group on transition from institutional to community-based care” of which Ms Sabrina Ferraina, Policy Manager is currently co-chair.

EASPD is part of the following institutional and civil society working groups and organisations:

* **Council of Europe**: EASPD is member of the Committee of Experts on the Rights of People with Disabilities;
* **European Commission**: EASPD is member of the High Level Group on Disability;
* **European Economic and Social Committee**: EASPD holds membership status with the NGO Liaison Group;
* EASPD is member of the **European Disability Forum**.

**Support service provision in Europe**

Support service provision in the disability sector has been undergoing substantial changes over the past years, and many services that were set up according to the medical-based approach to disability are currently moving away from this model towards the human rights model introduced by the UN CRPD, whereby needs and preferences of the individual are at the core of the attitude towards disability.

The reality, unfortunately, presents a picture that is complex and often not even close to the conditions required for the full enjoyment of human rights, as set in the UN CRPD. Persons with disabilities are frequently obliged to receive the services they need and are entitled to very far away from their homes and often in very low quality human and structural settings.

# Key issues for support services

The following represent in our opinion some crucial issues that need to be tackled as a matter of priority:

* The **size** of the residential centres. The settings are often very large structures and the users/staff ratio is too big to provide services in a qualitative, inclusive and individualised way.
* The presence of **institutional culture** which thrives at times also in smaller settings that, even when based in the communities, may present features common to large institutional and segregating settings.
* The **cross-border service provision**. The usage of a service that might be very far away from the place of origin of the family is often not the user’s choice, but is due to the unavailability of services in the nearby community.
* The **training and retraining of professionals** working with the users. Medical approaches are still widely used: the staff needs to be trained on human rights principles based on participation, inclusion and addressing users’ individual needs and preferences.

Responsive and effective quality community based services (CBS) depend on a flexible and well trained workforce and an adequate staff-ratio per user, as well as technical means to effectively provide them. Authorities shall provide legal frameworks facilitating adequate working conditions and decent jobs. To achieve a personalised approach, persons with disabilities should be involved as they are experts in the types of support that they require.

* **Quality standards**. Quality frameworks may vary according to the origin of the funding, having an impact on the end-service received by the user. In some countries indeed services and support are provided in a market model where for profit providers predominate. There is a danger in such scenarios of a two tier level of services emerging, with users who are able to pay enjoying good quality community based supports, while those unable to pay having access only to low quality institutional supports. Member States should avoid this by ensuring equal access to community based services for all. Equality and personalisation should be the focus of the development of community based services, not profit making.

Proper needs assessment instruments (including a quality of life approach) involving users and their families and individual future planning tools should be the basis of all service delivery mechanisms and should be legally binding.

Networking amongst providers and between mainstream and specialized providers should be part of Quality Assurance Systems and monitoring mechanisms. Quality systems should encompass a human rights perspective, focusing on the wishes and the preferences of the individuals, as well as on outcomes instead of on inputs.

* **Long waiting lists** prevent accessibility to services and have consequences at all levels.
* **Funding of services**. The delivery of quality support services that address individual needs requires sustainable and adequate funding streams. For-profit organisations may make a profit out of the delivery of their services at cheaper costs and with lower quality standards, therefore it is essential to have adequate Quality Assurance Systems in place to monitor and assess the enjoyment of human rights. International funding streams should be used to facilitate developments in the community and should set the example.
* **Legal capacity** of the users. Complaints filings are not always clear and supported-decision making procedures are not fully in place, limiting the expression of free will and choice. People with disabilities should be supported to achieve full citizenship and enjoy their rights as citizens to the full.
* **Cooperation with the housing sector**. The realisation of inclusive communities where people can live independently and receive support according to their needs and wishes can only be possible if individualised support services for persons with disabilities are part of a greater network with mainstream services. The development of community based services and residential facilities should build on a strong cooperation with the housing sector.

# 2. Comments on Article 19 UN CRPD

***“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:”***

People with intensive support needs and/or people from minority communities must be taken specifically into account when new services are planned, so that their needs are considered with the same urgency and priority as others who are making the transition to community-based services.

The use of **co-production methodologies** could allow the implementation of inclusive working practices with the ultimate goal to deliver a service that is responsive to the user’s needs and preferences.

**Article 19 paragraph a**

1. ***“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;”***

The successful implementation of reform plans leading to the development and set-up of community-based services requires a **strong coordination between all the relevant actors**, both at horizontal (various ministries, such as ministries of health and social affairs) and vertical (national and local authorities) level. Participation planning at national, regional and local levels as well as participative structures and bodies should be established; this includes also the promotion and support of independent self-advocacy groups.

**Article 19 paragraph b**

1. ***“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;”***

Services provided should be built around the concepts of person-centeredness and individualisation in order for them to be sensitive to the person’s needs and wishes. Universal design should be included in the service design.

Innovation in service provision should be fostered through structural involvement of persons with disabilities and their families.

The delivery of support services should be built on **empowering approaches** - which may include also direct payment systems - based on Quality Assurance Systems. Personal assistance schemes and respite services should be foreseen and made available as part of a general framework of support services.

A certain level of competition between services should be allowed in order to ensure the availability of sufficient support choices for the users, provided quality criteria are ensured.

**Article 19 paragraph c**

1. ***“Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”***

Welcoming communities are crucial for the development of community-based services; therefore, the public domain must be made accessible and ready to welcome people with support needs. The governments at all levels should make communication tools available to users, their families and the communities to facilitate full and effective inclusion of and participation by people with disabilities in their communities.

To ensure access to general services to persons with disabilities, a good cooperation and coordination between health and social services and between professional and non-professional supporters is essential. To this end, training programmes of future social, educational and health workers should be adapted to the UN CRPD human rights model of disability.

# 3. Specific comments on the paragraphs of the CRPD Draft General Comment

***Paragraph 24***

The exercise of choice can be effectively realised when individuals are made part of the decision-making act. **We would like to recommend the use of co-production methodologies** and approaches as a way to allow individuals to take ownership through active and meaningful partnerships. Through co-production all stakeholders are empowered and are empowering as they are continuously involved in a structural, meaningful and ongoing manner in the design, development and delivery of the service, policy or activity[[1]](#footnote-1). Co-production requires all stakeholders to acknowledge and recognise the expertise, desires, will and preferences of the person with support needs. Mechanisms must be put in place to ensure that people are provided with the right level of independent support, which empowers persons with disabilities to make fully informed decisions on how to engage in a co-productive process.

***Paragraph 27***

*“27. Article 19 (b) has to be interpreted in line with the human rights model of disability. Hence, individualised support services must be considered a right instead of a form of medical care or charity. For many persons with disabilities, access to a range of individualised support services is a precondition for independent and community living. Persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences”* ***and individualized support should be flexible enough to adapt to the users’ needs and not the other way around****.*

***Paragraph 88***

While sheltered work does not always represent the most inclusive work practice, the more innovative forms of **sheltered work can provide a bridge between persons with disabilities and the labour market**. Often this represents their only possibility to make a step into the world of work, therefore there is a need for sheltered work to be better connected with mainstream actors of society to strengthen the potential of inclusion of persons with disabilities. **Social economy enterprises** – which sometimes fall under the category of sheltered work, depending on national definitions - are a positive example of inclusion of persons with disabilities in the open labour market.

***Paragraph 89***

It is important to mark **the need for support services along the cycle of life of the individual, including the elderly stage of life** and ensuring the availability of support and residential-community based services also when family members and supported have passed away. Often, the lack of continuity and of permanent support to individuals in more inclusive-community-based settings obliges family-supporters to give priority to less inclusive services that guarantee support in the long-term, including when they will not be able to support their family members.

# 4. Relations with other Articles

* Article 8 (Awareness raising): Living independently leads to the recognition of people as full citizens with equal rights. The general population should become more and more familiar with societies that are truly inclusive and promote equal opportunities for all.
* Article 9 (Accessibility): Accessibility is fundamental to promote participation of persons with disabilities in society.

When it comes to accessibility implementation plans a truly comprehensive approach is needed, taking into consideration the needs of every individual and all aspects of the environment (i.e. education, work, culture, social participation, transport, leisure, etc.). The right to accessibility has to be guaranteed to persons with physical, sensorial, mental and intellectual disabilities that can have different sorts of needs.

Accessibility should therefore be understood as going beyond the idea of overcoming physical barriers, and it should include also technical and human support. Simplification of information (e.g. easy-to-read language), human support and ad-hoc tools are all equally essential to ensure full participation to persons with intellectual disabilities.

* **Article 12 (Equal recognition before the law):** Often the choice of residence in a place to live is jeopardized by the non-recognition of the individual’s legal capacity. It is therefore imperative for authorities to take measures that remove any obstacle to a person’s recognition before the law and at the same providing adequate support measures and systems to allow persons with multiple support needs to be able to express their views and avoid any undue influence, exploitation and abuse, both social and financial.
* **Article 24 (Education):** The possibility of living in an inclusive family-type of environment, based in the community and where the individual needs of each individual are duly taken into consideration is functional to the self-development of the individual and to his sense of belonging to a community. The emotional and physical wellbeing that can be attained in these settings can pave the way to inclusion in the education sector.
* Article 27 (Work and employment): The possibility for persons with disabilities to live in inclusive settings is a pre-condition to be empowered and become active citizens. As such, independent living also leads to the possibility of expand the independence of the person to other spheres of life that are equally important to be included in society. Successful employment can become a reality also when persons are empowered to live their lives independently with the support they require, being responsible for their own decisions.

# Conclusions

Fundamental changes in the services’ design and delivery are clearly yet to be fully accomplished in the policy and in the practice and they represent the challenge for the support service provision of tomorrow as well as for policy makers at national and international level.

Community-based services can become a reality for people with disabilities only when they themselves, their families and their providers of support services are involved in every stage of the planning, design, development and delivery of services. Society needs to be challenged on the big cultural shift needed to fully ensure the rights of persons with disabilities and respect for their dignity. A mind-set change will be more effective when it is accompanied with concrete changes in the lives of those who require support.

Mainstreaming of services should occur with and through all involved actors (i.e. persons with disabilities and their families, employers, housing corporations, professionals, public authorities at local/national level, health bodies), using the expertise of specialised support providers.

In the provision of community-based services, quality of life should be at the centre of the planning and it should not be confused with quality of services, although the latter contributes to the enjoyment of human rights and of a life of human flourishing and dignity.

Institutional culture and its negative consequences are not automatically eradicated with the dismantling of huge buildings; it can indeed thrive also in community-based services; therefore, frequent assessments, responsive to individual’s needs, wishes and preferences, are needed to monitor the measures taken and adapt them if needed.

Disability support services currently employ 10 million professionals who may represent a lever for change in the sector and are key players in the process of transition towards the human rights based model introduced by the Convention. Training of disability leaders and staff in support services is essential if we are to provide the correct support to persons with disabilities.

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1. See Common Definition of Co-production between EASPD, EDF, Inclusion Europe, ENIL, MHE and COFACE Families Europe: <http://www.easpd.eu/sites/default/files/sites/default/files/joint_declaration_v2_final.pdf> [↑](#footnote-ref-1)