COFACE DISABILITY MEETING, 13- 14 JUNE LUXEMBOURG

Discussion Paper for a COFACE Families Europe Community-Based Services Typology

INTRODUCTION:

The objective of this discussion paper is to give tools for discussion between COFACE members on:

- the implementation of article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), taking into account the needs of family;
- start defining together the new generation of services to replace institutional settings;
- develop a common COFACE conceptual definition of community-based services to be used:
  - In our advocacy work at European and national level;
  - As a reference tool in the development of new services / policy frameworks / funding streams in line with the CRPD and responding to the needs of families.

KEY CONCEPTS:

Institutionalised settings / institutions: Institutionalised settings can differ in size, name and setup; there are certain defining elements: obligatory sharing of assistants and no, or limited, influence over from whom one has to accept assistance, segregation from the community, lack of control over day-to-day decisions, lack of choice over with whom to live with, rigidity of routine, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach, supervision of living arrangements, disproportion in the number of persons with disabilities living in the same environment. [1]

An institution is any residential care where:

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have sufficient control over their lives and over decisions which affect them; and
- the requirements of the organisation itself tend to take precedence over the residents' individualised needs.

Smaller (in number of users) and more personalised living arrangements are more likely to ensure opportunities for choice and self-determination of service users and to provide a needs-led service. However, small size of accommodation does not in itself guarantee elimination of institutional culture: level of choice exercised by service users, level and quality of support provided and participation in the community are critical.[2]

De-institutionalisation: The process of closing of institutions, while establishing a new generation of services regulated by rights-based and outcomes-oriented standards. Deinstitutionalisation requires implementation of structural reforms which go beyond the closure of institutions. Closing institutions and relocating users must be accompanied by comprehensive service and family and community development programmes, including awareness programmes. Systemic transformation also includes the elimination of institutionalising regulations as part of a comprehensive strategy, along with the establishment of a range of individualised support services, including individualised plans for transition with budgets and time frames as well as inclusive support services.

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[1] Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU, FRA, 2017

[2] Common European guidelines https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf

Independent living: Independent living means that individuals with disabilities are **provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives.** Personal autonomy and self-determination are fundamental, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious, cultural and sexual, reproductive rights. These activities are linked to the development of a person's identity and personality. Independent living is an essential part of the individual's autonomy and freedom, and does not necessarily mean living alone. **It should also not be interpreted solely as the ability of carrying out daily activities by oneself.** Rather, it should be regarded as the **freedom to choose and be in control,** in line with the respect for inherent dignity and individual autonomy.

Independent living arrangements: Both independent living and being included in the community refer to life settings outside institutions. **It is not "just" about living in a particular building or setting, it is, first and foremost, about losing personal choice and autonomy as a result of the imposition of certain life and living arrangements.** Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization.[3]

Being included in the community: Being able to participate in society on equal basis with others. This involves having access to mainstream services such as schooling, health care, social housing, public transport, leisure and sport.

A policy framework allowing DI, allowing a real shift towards community-based services, should be based on an **evidence-based diagnosis of poverty and social exclusion** including:

- Disability poverty, including child poverty
- Homelessness
- Spatial and educational segregation
- Limited access to essential/basic public services and infrastructure

- The specific needs of people vulnerable to exclusion, and/or discrimination (e.g. on the basis of race, ethnicity, religion or legal status)
- The number of institutionalised children, persons with disabilities, older people, including new entries into institutions

Community-based services / care: The term 'community-based services', or 'community-based care', refers to the spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as supported living or personal assistance for persons with disabilities. In addition, the term includes family-based and family-like care for children, including substitute family care and preventative measures for early intervention and family support.

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[3] CRPD General Comment http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en

MAIN CHARACTERISTICS: Inclusion in the community / institutionalisation

	INCLUSION IN THE COMMUNITY	INSTITUTION
CONTROL OVER PERSON'S LIFE	The **person herself/himself decides based on personal preferences**. **Enough services** on offer to be able to choose from. **Support** to making the decision.	Person´s life subjected to **service regulations**. Staff decides about what, when will a user do a certain thing. "Choice" limited to deciding between a **limited number of options** on offer. **Not supported to make decisions**, including not being able to experience different forms of support and living arrangements.
LOCATION	Housing **separated from the location of daily activities** (school, work etc.), and well **connected** to mainstream services.	**Housing and daily activities in same location**. Housing located in an area **segregated** from the rest of society (by distance, by wall) and/or located in a **hospital-like** building.
STYLE OF SERVICE	**Individualised** in terms on **focus on** individual personal **needs** and **preferences**. Focused on **establishing and maintaining person's social roles** (employment, relations etc.) Using **mainstream services**.	**Group-based provision of service** (same type of activity at same time regardless of person's needs or preferences). Focused on **medically-defined needs**. **Substituting mainstream services with segregated alternatives** within the institution.

EXAMPLES of community-based services and infrastructure developments needed to achieve independent living

- Personal assistance
- Support for enhancing life skills and autonomy, including for people leaving institutions
- Day care, including activity and leisure centres in inclusive, community settings
- Technical aids and assistive technologies (e.g. social alarms, hearing and visuals aids, etc)
- Supported living, accessible housing, housing adaptations, etc.
- Non-segregated social housing within the community (e.g. housing first programme for homeless people)
- Accessibility of services and built environments, for instance transport, housing, public buildings, etc.
- Inclusive and non-segregated education-related measures, for instance, early childhood education and care, etc.
- Availability of, and arrangements for, children to attend mainstream day-care, kindergartens or schools
- Out-of-school care and after-school activities
- Employment-related measures, vocational and skills training
- Support for kinship carer/parent, support for foster carer/parent
- Strengthening of foster care/parents networks
- Crisis intervention and emergency services
- Social work, including counselling and advice services, including case work and appropriate referrals
- Respite care services

OUR PROPOSAL

We believe it would be useful (not to say essential) to define community-based services from the COFACE perspective, highlighting the importance of support to families in the transition away from institutions. If we do not set this agenda and define services, they are likely to be defined anyway and not necessarily involving families in the process. This is why we would like to propose that COFACE adopts a typology of community-based services. If adopted in Luxembourg on 14th June, this could be A 'Luxembourg declaration'.

INCLUSION IN THE COMMUNITY	European	National
CONTROL OVER PERSON'S LIFE / **PERSONAL AUTONOMY**	The **person herself/himself decides based on personal preferences**. **Enough services** on offer to be able to choose from. **Support** to making the decision.	• Personal budget schemes • Personal assistance • Support for enhancing life skills and autonomy, including for people leaving institutions • Availability of technical aids and assistive technologies •Supported living, accessible housing, housing adaptations, etc.
SOCIAL INCLUSION	The person is able to participate in society **on equal basis with** others.	• Access to mainstream services such as schooling, health care, social housing, public transport, leisure and sport • Accessibility of built environments, public buildings, etc. • Inclusive and non-segregated education-related measures, availability of, and arrangements for, children to attend mainstream day-care, kindergartens or schools, Out-of-school care and after-school activities • Employment-related measures, vocational and skills training • Strengthening of foster care/parents networks
STYLE OF SERVICE	Housing **separated from the location of daily activities** (school, work etc.), and well **connected** to mainstream services. **Individualised** in terms on **focus on** individual personal **needs** and **preferences**. Focused on **establishing and maintaining person's social roles** (employment, relations etc.) Using **mainstream services**.	• Day care, including activity and leisure centres in inclusive, community settings • Crisis intervention and emergency services • Support for kinship carer/parent, support for foster carer/parent • Social work, including counselling and advice services, including case work and appropriate referrals • Respite care services

KEY QUESTIONS FOR COFACE MEMBERS:

- **Does the description of community based-services reflect the reality of your organisation and of your country?**

- **What's missing from a family perspective?**

- **In the setting of community services, which are the priorities to make independent living a reality?**

- **What could be the added value of COFACE Families Europe in this discussion? Which elements of a strategy of building a new generation of services?**

- **What key activities could we work on together in the future to support the implementation of UNCRPD article 19? Some ideas: Study on the challenges in the implementation, Reflection paper on the family dimension of DI, collection of good practices.**

EU FRAMEWORK documents

- [Common European Guidelines on the Transition from Institutional to community-based care](#), European Expert Group on the Transition from Institutional to Community-based Care, 2012
- [Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care,](#) European Expert Group on the Transition from Institutional to Community based care, 2014
- [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCRPD), United Nations, 2016
- [General comment No. 5 (2017) on living independently and being included in the community](#), United Nations, 2017
- [United Nations Convention on the Rights of the Child](#), United Nations, 1989
- [Guidelines for the Alternative Care of Children](#), United Nations, 2010
- [Moving Forward: Implementing the 'Guidelines for the Alternative Care of Children'](#) Centre for Excellence for Looked After Children in Scotland (CELCIS) at the University of Strathclyde; International Social Service (ISS); Oak Foundation; SOS Children's Villages International; and United Nations Children's Fund (UNICEF), 2012
- [Opening Doors for Europe's Children Campaign](#)
- [Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds](#), Structural Funds Watch, 2017
- [Getting a life: Living Independently and Being Included in the Community](#), A Legal Study of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, United Nations Human Rights Office of the High Commissioner, 2012
- [Country studies for the project on the right to independent living of persons with disabilities: Summary overview of types and characteristics of institutions and community-based services for persons with disabilities available across the EU](#), European Union Agency for Fundamental Rights (FRA), 2017
- [From institutions to community living - Part I: commitments and structures](#), FRA, 2017
- [From institutions to community living - Part II: funding and budgeting](#), FRA, 2017
- [From institutions to community living - Part III: outcomes for persons with disabilities](#), FRA, 2017
- [From institutions to community living for persons with disabilities: perspectives from the ground](#), FRA, 2018