

Analytical paper on Mainstreamed and community-based services

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I. Introduction

This paper aims to provide a resource to service providers and policy makers in understanding community-based services, de-institutionalisation and mainstreamed service provision for people with disabilities. It starts with presenting analysis of experience from EPR members who have developed successful mainstreamed or community-based service provision, including service-provider oriented proposals on how to ensure strong mainstreamed community-based services. Some key points raised at the 2015 Public Affairs event on mainstreaming are presented, followed by political recommendations from EPR to support community-based services.

The paper then outlines key EU and international initiatives in the field. The EU resources available for community-based care are outlined, along with criticism of the misuse of funds intended for this aim. Other initiatives addressed are the UN Convention on the Rights of Persons with Disabilities, the EU Disability strategy and the work of the European Expert Group on the Transition from Institutional to Community-based Care. An explanation of the Group's definition of "institution" is included.

2. EPR Members' experiences

2.1 EPR "*Study of services to support the inclusion of persons with disability in mainstream environments*"¹

In November 2015, EPR published the "*Study of services to support the inclusion of persons with disability in mainstream environments*" that aimed to provide evidence of trends and developments in delivery of services to people with disabilities. This study presents services from the EPR membership that support the inclusion of persons with disabilities in mainstream environments. It intends to be a useful resource for service providers, for disability communities, and for policy-makers. It also aims to provide disability service providers with ideas for possible innovations in the contents of service delivery, but also with insights into practical improvements in the methodology and processes supporting services. This study has thus a very hands-on mission to disseminate and support good practice. Representative associations of people with disabilities may find in it an advocacy resource to advance community inclusion and argue for de-institutionalisation and access to mainstream services in community-based environments.

The report highlights practices that support inclusion of people with disabilities in mainstream environments. By "mainstreamed environment" we mean the common society, that is, environments that are not segregated or targeted exclusively to persons with disabilities. It covers several dimensions of service provision, notably the following questions:

- How do EPR members support people with disabilities in accessing mainstream settings?
- How do EPR members deliver specialised services in mainstream settings?
- How do EPR members cooperate with mainstream organisations/ institutions/services?
- How do EPR members develop disability mainstream awareness?

¹ Authors: Paula Campos Pinto, Ph.D. and Teresa Janela Pinto, ICSCP/ Universidade de Lisboa. Available at http://www.epr.eu/images/EPR/documents/Studies/EPR_Study_Mainstreaming_Services_2015_Final.pdf

2.2 Summary of report findings

One of the first challenges faced in service provision is ensuring adequate and sustainable funding to develop the programme. Most programmes rely on some level of public funding, but even when such funding is available, it is often insufficient to cover all expenses, especially as programmes develop and expand with new clients. Pilot programmes may face some added challenges at this level, since not all income and expenses are determined in advance.

Secondly, the programmes are faced with challenges concerning the selection, involvement and ongoing motivation of the clients and other stakeholders. In most programmes, one of the main challenges is ensuring that the clients and other stakeholders (e.g. mentors, workers and partners) stay motivated and engaged throughout the programme and after its completion. Programmes are frequently faced with high withdrawal rates. For this reason, several programmes mentioned working with the clients towards building intrinsic motivation and engagement with the project's goals.

Thirdly, the programmes are faced with the need to respond to challenges arising from their own methodological choices. Some programmes imply a certain degree of unpredictability, resulting from the continuous adjustment between the professionals and the clients' needs. Another methodological issue concerns the challenge of balancing an individualised approach to coaching and support while ensuring that the methodology retains some uniformity.

Finally, economic and institutional barriers can represent a challenge to the programmes' success, such as the overall economic context and the lack of work opportunities for persons with disabilities, or regional disparities in the level of inclusiveness of employment services.

The opportunities identified by the programmes revolved around four themes:

- a) Expanding opportunities for capacity-building and inclusion of the target group in a mainstreamed environment, whether in the scope of education, employment or social participation;
- b) Using these programmes to test innovative methodologies to promote inclusion and potentially scale them up region- or nation-wide;
- c) Using these programmes to raise awareness in the communities and support the creation of more inclusive environments.
- d) Finally, some programmes mention the opportunity to create or reinforce the links with other initiatives, in order to develop a more comprehensive approach to social inclusion.

2.3 Practice – recommendations for strong mainstreamed/community-based services

One of the points highlighted in the report as a suggestion to strengthen the programme was the need to ensure the engagement of the target-group throughout the programme. The success of the programmes requires paying attention to any oscillation in the motivation of the participants and developing personalised strategies to keep them engaged with the programme's goals. Similarly, the need to expand and consolidate a network of partnerships, including other service providers, non-profit organisations, public and private companies, community structures and public authorities, should be considered. Another point highlighted by some of the programmes was the need to increase the number of activities developed in mainstream environments or involving other stakeholders, such as community members, families and other professionals. Some programmes also

expressed the need to reinforce funding so as to enable the programmes' consolidation and expansion or improve service provision. Finally, the organisations left some suggestions for strengthening programmes through good monitoring and evaluation procedures and external research studies that may provide insights concerning the strengths and weaknesses of each programme, through investment in strong multi-disciplinary teams, or through a gradual approach to programme expansion, starting small and building on success.

In terms of programme recommendations, it is possible to draw six recommendations for future directions from the EPR study. These recommendations are in line with the principles and standards of the UN Convention on the Rights of Persons with Disabilities and reflect the EPR Charter on Modernisation of Disability-related Health and Social Services.

Programmes should:

- a) *Enhance the capacity of persons with disabilities and develop transition programmes*

This recommendation is echoed in Pathway 3 of the EPR Charter, which states that disability-related health and social services should actively contribute to enhance the capacity of individuals to participate fully in society.

- b) *Be person-centred and take a rights-based approach*

This suggestion is in line with Pathway 6 of the EPR Charter, which states that service users should be involved in all aspects of their (re)integration process with a view to maximising their potential and realising their aspirations.

- c) *Promote "mainstreaming" through a twin-track approach*

In order to achieve full participation for persons with disabilities, across a wide range of ability levels, it is necessary to develop services as close to the mainstreamed environment as possible, while providing any necessary specialised support to facilitate inclusion. This recommendation is in line with Pathway 4 of the EPR Charter, which states that mainstreaming should be pursued through a twin-track approach that integrates a mainstreaming model with specialised solutions for people who find it hard to integrate in the mainstream. The analysis of the experiences of some EPR member organisations presented in this study suggests that in these cases the inclusion in mainstream environments can be accomplished on a gradual basis, through capacity-building strategies undertaken within a semi-protected environment. The number of activities in mainstreamed environments will be gradually increased throughout the programme in order to make the transition as smooth and sustainable as possible.

- d) *Develop strategic partnerships with mainstream organisations and actors*

Full participation of persons with disabilities will not be achieved without the involvement of mainstream organisations and actors. Developing partnerships is a way to ensure a maximum complementarity of approaches by sharing resources and knowledge, and making full use of each partner's area of expertise, as suggested in Pathway 4 of the EPR Charter.

- e) *Promote and facilitate inclusive environments*

While recognising that most EPR member organisations are focused on service provision, rather than on advocacy efforts, activities designed to promote disability mainstream awareness in regular service-provision programmes are worth being recommended. These strategies simultaneously work

with the clients (persons with disabilities), to build their capacity and support their transition to mainstreamed environments, while acting on those very environments, in order to render them more inclusive of the needs of persons with disabilities. Such a comprehensive approach to mainstreaming issues reflects the spirit of Article 1 of the UNCRPD, which recognizes that disability emerges when persons with impairments encounter environmental barriers preventing their full participation

f) *Strive to achieve political support for disability mainstreaming*

Taking into account the previous recommendation, disability awareness and education of policy-makers and other stakeholders are therefore necessary steps and must emphasize the importance of considering disability in the design, implementation and evaluation of all policies and programmes, across all areas of society.

2.4 Key points from EPR Public Affairs event

EPR held its annual Public Affairs Event on 18 November 2015 in Brussels. It gathered European stakeholders in order to explore how specialized service providers can best promote the inclusion of persons with disabilities in the workplace and community and design effective support in the mainstream environment.

At the event, speakers called for more actions to ensure that the rights of people with disabilities are met, and for some member states to move much faster to ensure access to community-based services and personal assistance, and more generally, to implement the UNCRPD. The gap between need and investment as regards accessibility and specialised services was pointed out, and the role of people with disabilities in policy debates was stressed. The European Network on Independent Living (ENIL) stressed the importance of enabling people with disabilities to take up their rights and designing services that are tailor-made to people's needs. More awareness-raising campaigns should be organised, in particular inside the EU and national institutions, to support the mainstreaming of disability into all policy areas.

Ms Holst, Vice-chairperson of the Disabled Peoples Organisation Denmark emphasised the importance of supporting networking of people with disabilities and in employing them in service providers to ensure the services meet needs of the clients or service users. Frank Sioen from ENIL stated, "mainstreaming is an opportunity for service providers to be a front runner on the path towards an inclusive society where services are designed for and with the users".

2.5 Political recommendations from EPR “Study of services to support the inclusion of persons with disability in mainstream environments”

Five key recommendations were drawn up addressed to decision-makers to promote and support community-based services, based on the challenges and opportunities identified by the service providers in the EPR report.

a) Ensure sufficient, sustainable funding of mainstreamed disability services

Funding authorities must think long term, taking a social investment approach to financing social and employment services, recognising the value and future impact of effective mainstreamed services. The EU should strongly promote the social investment approach.

b) Allow flexibility in funding pilot programmes

Funding authorities should not be afraid to take risks in financing programmes in development. They should not cut funding if an approach is not as effective as anticipated, but adapt funding as the approach develops, to fit needs.

c) Assess and ensure the inclusiveness of public employment, education, housing and leisure services

Public authorities should assess the accessibility and inclusiveness of their employment, education, housing and leisure services and take action to ensure that people with disabilities do not miss out on the support available to them in this field.

d) Build understanding among employers of the UNCRPD and of reasonable accommodation

Public authorities and the European Commission should work with service providers to people with disabilities to explain obligations under the UNCRPD and the feasibility of workplace adaptation.

e) Develop and support initiatives that tackle socio-cultural barriers to the inclusion of people with disabilities in society in general and in the labour market in particular

Public authorities and the European Commission should work with stakeholders to develop campaigns and information material to dispel prejudices and show the benefits that a diverse workforce can bring.

f) Use the EU tools and funds available to develop and support community-based services

The European Commission should promote good practice in the use of EU funds for community-based services and de-institutionalisation. Member states' authorities managing EU structural funds must ensure projects funded are compatible with the UNCRPD and seek to learn from good practice. [This issue is further addressed later].

3. EU and international level activities

3.1 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The aim of the UNCRPD is to elaborate in detail the rights of persons with disabilities and set out a code of implementation. Countries that join in the Convention engage themselves to develop and carry out policies, laws and administrative measures for securing the rights recognized in the Convention and abolish laws, regulations, customs and practices that constitute discrimination (Article 4). Article 19 of the Convention sets out the right of disabled people to living independently and being included in the community².

² <http://www.un.org/disabilities/default.asp?navid=15&pid=162>

The EU as a signatory has also committed to the same engagements. The UN CRPD Committee, which monitors whether the European Union is properly implementing the CRPD, expressed its concern that EU funds have been used to finance institutions, in violation of the right to independent living in October 2015:

*The Committee recommends that the European Union develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. The Committee also recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.*³ In addition, the Committee criticised austerity measures that resulted in cuts in social services and support to families and community-based services.

3.2 Disability strategy 2010-2020

The European Disability strategy 2010-2020⁴ provides the framework for empowering people with disability to fully participate in society and ensure they can enjoy their fundamental rights. The strategy reiterates that the EU committed to promote the participation of disabled people in leisure activities, employment, education, health, social services and to achieve the transition from institutional to community based care.⁵

This Strategy provides a roadmap for the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), to which the European Union is a party since January 2011. It focuses on eliminating barriers in 8 areas reflecting the rights enshrined in the UN CRPD: accessibility, employment, inclusion education and training, equality, participation (including access to quality community-based services), health, social protection and external action. All these issues are of a great importance for people with disabilities and their families, and they should be addressed in a comprehensive way to ensure that the obstacles that they face are also removed.

For each area, the Strategy formulates some action lines, primarily to be performed at the national level. A “Commission Staff Working Document”⁶ that complements the EU Disability Strategy 2010-2020, contains a list of concrete actions that constitutes an initial implementation plan for the period 2010 – 2015.

Transition from institutional to community-based care has been identified as one of the priorities in the European Disability Strategy 2010 – 2020 to enhance the participation of people with disabilities in society on an equal basis with others. At this end the Commission identifies the Structural Funds and the Rural Development Fund as key financial instruments to supporting “the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions”⁷.

³ www.ec.europa.eu/social/BlobServlet?docId=14429&langId=en

⁴ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>

⁵ http://ec.europa.eu/regional_policy/en/policy/themes/social-inclusion/desinsti/

⁶ Commission Staff Working Document “Initial plan to implement the European Disability Strategy 2010-2020 List of Actions 2010-2015”, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=SEC:2010:1324:FIN:en:PDF>

⁷ European Disability Strategy 2010-2020 page 6, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>

In relation to community-based or mainstreamed services the Commission committed to work to:

- Develop and disseminate a quality framework for community-based services which will be based upon the European quality for Social Services of General Interest which was launched by the Social Protection Committee on October 2010⁸. This has not yet been developed.
- Promote the exchange of good practices among Member States in the Disability High level group on the personal assistance funding scheme.

EPR developed an analytical paper on personal assistance schemes across Europe for further information about this topic and its progress across Europe.

In December 2015, having reached the halfway point in its implementation, the European Commission launched a public consultation⁹ in order to assess the impact of the European Disability Strategy to date and to ensure EU policy remains tailored to the needs and rights of persons with disabilities.

3.3 European Structural and Investment Funds

The regulations governing the use of the European Structural and Investment Funds (ESIF)¹⁰ for 2014 to 2020 clearly mention that the one of the “investment priorities” is funding the transition from institutional to community-based care. To achieve the thematic objective of promoting social inclusion and combatting poverty, Member States are required to fulfil an “ex ante” conditionality according which they should introduce measures on deinstitutionalisation (DI) and include civil society organisations in decision-making. Building or renovating long-stay residential institutions is excluded from the ESIF support, regardless of their size. Measures proposed are part of a strategic vision on how the transition from institutional to community based care will be implemented¹¹

For the European Regional Development Fund, the objective is to improve access to high quality services through investments in mainstream health and social infrastructure, education, housing and specialised services, prevent institutionalisation and support the reforms for the transition.

[Thematic guidance note on Transition from Institutional to Community-based Care \(Deinstitutionalisation\)](#)

This document aims to support Commission officials working with the EU funds to ensure that the Member States use the funds for DI and community-based services. They provide information that would also be useful for public authorities and providers looking to see how the funds could be used to promote community-based services.

⁸ Not yet adopted. See “*Opinion of the European Economic and Social Committee on long-term social care and deinstitutionalisation*”: The EESC urges the European Commission to adopt a European Quality Framework for community-based services and reiterates the urgent need for strict, binding standards to ensure the highest levels of quality. Available at <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52014AE7336>

⁹ Survey page <http://ec.europa.eu/social/main.jsp?langId=en&catId=1137&newsId=2421&furtherNews=yes>

¹⁰ See http://ec.europa.eu/contracts_grants/funds_en.htm

¹¹ http://ec.europa.eu/regional_policy/en/policy/themes/social-inclusion/desinsti/

3.4 European Expert Group (EEG) on the Transition from Institutional to Community-based Care¹²

The EEG is a broad coalition gathering stakeholders representing people with care or support needs including children, people with disabilities, people experiencing mental health problems, families; as well as service providers, public authorities and intergovernmental organisations¹³. The group was established by the European Commission in 2009 and contributed to the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community Based Care and the Common European Guidelines on the Transition from Institutional to Community Based Care, outlined below, in 2012. The documents are available in over ten languages. A revised edition of the English language version was published in 2014.

The Group's mission is the promotion of person-centred, quality and empowering models of services and formal and informal care that fully respect the human rights of all people with care or support needs. The Group supports national efforts to implement the necessary reforms, in compliance with the United Nations Convention on the Rights of Persons with Disabilities (in particular with Article 19), the United Nations Convention on the Rights of the Child and the European Fundamental Rights Charter. The Group provides expert support on EU policy, legislation and funding.

The approach of the group's regarding de-institutionalisation has been getting rid of the "institutional culture". The de-institutionalisation drive does not rule out residential care settings per se, if they provide the right level of inclusion, engagement and choice, for example. The guidelines state that and "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.

At the same time, size is an important factor when developing new services in the community. Smaller 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. (p27)

[Toolkit on the Use of European Union Funds for the Transition from Institutional to Community Based Care](#)

This toolkit developed by the EEG aims to explain how EU funds can support national, regional and local authorities in designing and implementing structural reforms aimed at facilitating the development of quality family-based and community-based alternatives to institutional care. The transition from institutional to community-based care is a complex process which requires additional resources, especially at the beginning of the process and while both systems are running in parallel. It

¹² <https://deinstitutionalisation.com/>

¹³ They are COFACE (Confederation of Family Organisations in the EU), EASPD (European Association of Service Providers for Persons with Disabilities), EDF (European Disability Forum), ENIL-ECCL, ESN (European Social Network), Eurochild, FEANTSA (European Federation of National Organisations Working with Homeless People), Inclusion Europe, Lumos, MHE (Mental Health Europe), OHCHR (Office of the High Commissioner for Human Rights, Europe Regional Office) and UNICEF.

entails “the development of quality services in the community, the closure of long-stay residential institutions and the transfer of resources from the institutional system to the new services, thus ensuring long-term sustainability”. It also involves ensuring that mainstream services such as healthcare, labour market services and education and training are accessible and available to all. The Structural Funds offer an opportunity to be able to invest in services which give individuals choice and control over what services are delivered and how. The ESF can also provide funding to pilot different, innovative approaches.

[Common European Guidelines on the Transition from Institutional to Community Based Care¹⁴](#)

The Common European Guidelines on the Transition from Institutional to Community-based Care provide practical advice about how to make a sustained transition from institutional care to family-based and community-based alternatives for individuals currently living in institutions and those living in the community, often without adequate support; for children, persons with disabilities, persons with mental health problems and older persons in Europe. It addresses different phases of the Transition. The Guidelines are aimed primarily at policy and decision makers in the European Union and the neighbouring countries.¹⁵

3.5 “Community, Not Confinement: The Role of the European Union in Promoting and Protecting the Right of People with Disabilities to Live in the Community” by Israel Butler

The report “Community, Not Confinement¹⁶” focuses on how the European Commission can ensure that Member States optimise the use of structural funds to support independent living. At the EPR Public affairs event Dr Israel Butler, author of the report, highlighted that to make this happen the Commission needs to give Member States better guidance on how EU law requires them to implement the UN CRPD and to improve the level of information on how Member States are using structural funds. It is crucial for the European Commission to monitor investments’ compliance with the regulations governing EU structural funds and make effective use of the sanctions¹⁷ whether contraventions are detected.

Millions of euros were invested in institutions under the last programming period and the report finds that there is a real risk that structural funds will continue to be invested in institutions through projects that do not comply with the right to independent living (article 19 of UN CRPD). In some countries the long tradition of institution-based care prevents to make changes in short term and local governments need support the transition to community-based services by adopted the legal framework and organising training of civil servants.

The report identifies the reasons that lead to this situation:

Lack of awareness: national authorities are not aware that EU law obliges them to comply with the UN CRPD when spending EU structural funds.

¹⁴ <http://deinstitutionalisationguide.eu/>

¹⁵ <http://www.socialserviceworkforce.org/resources/common-european-guidelines-transition-institutional-community-based-care>

¹⁶ Full report available at <https://www.opensocietyfoundations.org/sites/default/files/community-not-confinement-20151014.pdf>

¹⁷ See Structural Funds Regulations <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32013R1303>

Inadequate monitoring: the Commission has not requested sufficiently detailed information from national authorities about how they will ensure compliance with the UN CRPD when they formulate selection criteria and carry out internal checks that projects comply with EU law, nor when Member States report to the Commission on how they are spending EU funds. The Commission should check the Operational Programmes and fulfilment of *ex ante* conditionality by Member States in light of the requirements of the CRPD on independent living. The Commission should also ensure it has enough information to spot projects that could breach the rules by funding civil society organisations to monitor Member States.

Weak enforcement: the new legislation on structural funds has made monitoring even weaker than before. Under the old rules, the Commission was willing to deal directly with complaints about how EU structural funds were being used. Under the current rules, it intends to refer these complaints back to national authorities to deal with and it will not check whether the outcome of complaints ensures compliance with the UN CRPD. The Commission should ensure effective channels for complaints from civil society organisations concerning misuse of EU funds, investigate such complaints and take corrective measures, including the application of financial corrections and the interruption and/or suspension of payments when national authorities are violating the CRPD.

Weak participation: many Member States have failed to adequately include civil society organisations representing persons with disabilities in decision-making. This makes it less likely that civil society organisations can help to prevent the selection of projects that violate the right to independent living. The Commission should ensure that Member States include civil society organisations in the implementation phase of the structural funds.

At the EPR Public affairs event Dr. Butler recommended more awareness-raising and information campaigns to tackle misunderstandings around de-institutionalisation amongst policy makers and to inform them of their obligation to implement the CRPD through the funds. He recommended more site visits and audits of EU funded projects. He also emphasised the need to spread good practices and to show the real-life dimension of the impact of community-based services, to put the emphasis on developing community-based services rather than on abolishing institutional care.

The European Platform for Rehabilitation (EPR) is the Network of providers of rehabilitation services committed to excellence and innovation. EPR and its members contribute to a society where every person with a disability and persons in other vulnerable situations have access to the highest quality services that create equal opportunities for all and independent participation in society. More information on www.epr.eu

