GUIDANCE FICHE NO XXX

Transition from institutional to community-based care (de-institutionalisation - DI)

Regulation	Article
CPR	Article 19, Annex V: Thematic and general ex-ante conditionalities
ESF Regulation	Article 3: Scope of support **(b)** Promoting social inclusion , combating poverty and any discrimination through: (i) Active inclusion **in particular with a view to promoting equal opportunities and active participation, and improving employability**; (iv) Enhancing access to affordable, sustainable and high-quality services, including health care and social services of general interest;
ERDF regulation	Article 5: Investment priorities (9) promoting social inclusion, combating poverty and any discrimination • investing in health and social infrastructure which contribute to national, regional and local development, reducing inequalities in terms of health status, and transition from institutional to community-based services.
EAFRD regulation	Article 5: Union priorities for rural development (6) promoting social inclusion poverty reduction and economic development in rural areas

1. Rationale for the policy and main objectives

A study funded in 2007 by the European Commission[1] found that more than one million people with disabilities live in institutions across Europe. These concern mostly people with disabilities, mental health problems, older people or children deprived of parental care but may also include other group at risk of poverty as ethnic minorities. Institutions were originally seen as the best way of caring for vulnerable children and adults with a variety of support needs. However evidence has shown that institutional care provides poorer

[1]Deinstitutionalisation and community living: outcome and costs: http://inclusion-europe.org/en/projects/past-projects/decloc-report

outcome in term of quality of life compared with quality services in the community as they cannot ensure the person- centred approach and appropriate support needed to bring about full inclusion.

Nevertheless attaining full economic and social participation of people with disabilities is essential for progressing towards the EU 2020's headline targets and its overall objectives.

The European Disability strategy 2010-2020 provides the framework for empowering people with a disability to fully participate in society and ensure they can enjoy their fundamental rights. The strategy reiterates the EU commitment to promote the participation of disabled people in leisure activities, employment, education and health and social services and to achieve the transition from institutional to community based care.

The strategy aims also to facilitate the implementation of the UN Convention on the rights of persons with disabilities (CRPD), to which the EU is party since January 2011. This implies that the rights enshrined therein needs to be promoted and respected by the EU in its legislative actions as well as in its policy making to the extent of its competences. Among the key articles of the Convention relevant for deinstitutionalisation, article 19 lays down the right to an independent living.

Taking into consideration the broader definition given in art1 of the CRPD, people with mental health problems have the same rights as other groups of people with disabilities and all provisions of the Convention apply to them on an equal basis.

In the Council Conclusion of 6 June 2011 on "The European pact of mental health and well-being: results and future action" the Council invites Member States and the Commission to promote, where possible and relevant, community-based and socially inclusive care models to mental health.

As in the case of adults it is difficult to have reliable data on the number of children in residential care. Nevertheless a recent Eurochild survey estimates that approximately 1 million children live in state/public care in 30 European countries.

Therefore the recently adopted Commission recommendation on child poverty (as part of the Social Investment Package) invites MS to address child poverty and children's well-being through an integrated approach which would involve ensuring access to adequate income and living standards and empowering children through access to quality services. In so doing the recommendation emphasises the importance of family support (including preventive services) and quality alternative care for preventing as much as possible the children's removal from their family setting and in case this is needed, to offer a quality support including in the transition to adulthood.

2. How to operationalize the policy theory with regard to the funds?

Structural funds can support a wide range of measures including cross sectorial initiatives to accompany reforms in the Member States.

It is suggested that the measures proposed are part of a strategic vision on how the transition from institutional to community based care will be implemented, in line with the criteria under the proposed ex-ante conditionality for active inclusion. The strategy should be designed and implemented in consensus with services users' representatives, service providers and relevant stakeholders. The strategy should address long-term sustainability, including of the continued operation of infrastructure beyond the timespan of the

programme. Account should be taken of that while extra costs will arise during a transitional phase, the progressive closing down of larger institutions should allow for the reallocation of existing national budgetary resources to the new facilities.

Measures proposed could include:

- Measures preventing the need for institutionalisation.
- Measures to develop services based in the community enabling people to live independently
- Measures for enabling access to mainstream services (education and training, employment, housing, health, transport, leisure activities) to everyone, regardless the nature of their impairment, are in place.

The proposed measures should be based on an analysis of the situation and the needs, including an assessment of the needs of the population at risk of institutionalisation, the availability of services in the community (e.g. the number and range of services provided in the community (including preventive services); the financial, material and human resources; disaggregated data about individuals with support needs living in the community and individuals living in long-stay residential institutions; access of children and adults with support needs to mainstream services) and the causes of institutionalisation of children and adults which may include poverty, lack of services in the community, stigma etc. This analysis should also be reflected in the funds' contribution to the integrated approach set out in the Partnership Agreement to address the specific needs of geographical areas most affected by poverty or target groups at highest risk of discrimination or exclusion. Experience of the current programming period has shown that the integrated use of funds - including EU and national funds - is indispensable in the programming of DI measures. It may have relevance for establishing multi-fund interventions on different levels of programming. The implementation phase may require a strong coordinating entity at national level, backed up by a strong partnership involving all relevant stakeholders.

Measures could both prevent institutionalisation and support the reforms for the transition when shifting from one model to the other. Prevention measures should focus on the access to high-quality education, social care, healthcare services, and to eliminate all barriers. The access may depend on the social status of the children or adult, the physical availability of the services, on ethnic discrimination, and all these aspects should be taken into account in the design of the ESIF investments. The general poverty alleviation measures may also play an important role, as in some cases children are put in the institutions because of poverty reasons. The shift to community-based care may encompass investments in small scale, community-type services ensuring the basic conditions for independent living for target groups, notably the physically and mentally disabled as well as children.

Implementation of a strategy requires an integrated use of both ESF and ERDF.

Examples of ESF measures to be funded:

- drawing up an action plan on the transitions to community based care which would include individual care support and preparation for each service users involved.
- ensuring continuity and stability in service delivery during the shift from one model to the other. This includes supporting the development of new services especially at the beginning of the process when both systems are running in parallel.

- development of an integrated network of community based services such as: personal assistance, home care, family counselling, day care, job search assistance, nursing, foster care, etc. Integrated services would enable people to leave residential care and live in the community with appropriate support.
- Improving access to mainstream services such as education, healthcare and transport
- staff re-training especially where there is a shift of model (training institutional care staff to work in new community based services)
- curriculum development for posts in community based services and mainstream services
- improving the status and professionalization of social services
- create support for families and informal carers
- awareness raising activities for people with support needs at risk of exclusion in order to inform them about their rights
- In the case of children in alternative care, the provision of family-based or family-like care which includes family support.

Examples of ERDF measures to be funded:

- Development and adaptation of social, health and education infrastructures for the provision of community-based services
- Improving the quality and capacity of existing infrastructures for community-based services
- Plans for the future of institutional infrastructure (buildings and material resources), provided it is used for different purposes that do not involve the provision of residential care for any group; plans should be made for a viable and logical reuse of the building and should not be approved if the costs of investment in the building outweigh the benefits
- Development of accessible housing for people with disabilities in the community
- Development of supported housing options integrated in the community
- Investment in social housing which will be available to those leaving institutional care or at risk of being institutionalised
- Home adaptation (introduction of e-health services)[2]
- Development of childcare infrastructure in the community
- Development of infrastructure for family-like placements for children (small group homes) in the community, in line with the UN Guidelines for the Alternative Care of Children[3]

The cost-benefit aspect of the programs for shift to community-based care is an important argument for reinforcing the need for further programs. In general, evidence shows that

2Further information about the use of e-services at the community, family level: http://www.aal-europe.eu/,

3 Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care - http://deinstitutionalisationguide.eu/wp-content/uploads/2012/11/Toolkit-11-02-2012-final-WEB.pdf

after deinstitutionalisation measures the costs remain broadly the same (or may slightly increase), but the quality of life of service users and their satisfaction with services will improve. Community-based care is, overall, more cost-effective than institutional care.[4]

Building or *renovating* long-stay residential institutions is excluded, regardless of their size. Note that the size of the institution cannot be used in isolation as a criterion to judge whether the supported infrastructure can be considered as community-based service or simply a scaled-down institution. The starting point should be whether it provides a setting allowing for the possibility for independent living, inclusion in the community (including physical proximity of the location) and high-quality care. However, it is clear that the larger the infrastructure the more likely it is that these criteria will not be fulfilled.

Improvements in existing institutional infrastructure can only be financed in restricted cases, such as:

- the use of these institutions forms part of a wider strategic programme for community living but they will be phased out in the course of the transitional process; and
- the persons concerned, given the seriousness of their condition, require constant medical supervision.
- Other clearly identified and compelling cases

It should be noted that determination of the fulfilment of criteria concerning size and the above-mentioned restricted cases are judgemental in nature. Therefore, it should be ensured that the partnership principle is duly applied in the application of these criteria so that adopted solutions represent a consensus between stakeholders (government, NGOs and service user representatives.

The proposed measures should provide evidence on the real needs they envisage to address and a justification of the objectives. The description should inform on how the action will facilitate the social inclusion of the target group. Assurance should be provided that any group of individuals will not be excluded from the support because of the type of their impairment (e.g. because of the complexity of their support needs).

Support to services in living units should facilitate independent living or, in the case of children, family-like care. Furthermore, support should not be conditional to one particular housing arrangement (individuals will not be obliged to choose a particular living arrangement because of the availability of support).

Service users and where relevant families should be involved in the design of the supported service.

3. Good/bad practices and examples

"Childhood for All" – Bulgaria

The total duration of the project is 54 months (June 2010–December 2014) which represents the main pillar of Bulgaria's on-going de-institutionalisation reform as it strives to create a sustainable model of transition from residential to community-based services for children with disabilities.

[4] Further info: Common European Guidelines on the Transition from Institutional to Community-based Care (www.deinstitutionalisationguide.eu)

The project consists of two components, which ESF has financed under the OP "Human Resources Development" "Planning of measures for deinstitutionalisation" (2.5 MEUR) and "Provision of community-based social services" (16.5 MEUR). The ERDF and the EAFRD have allocated 44.8 MEUR and 8.5 MEUR respectively, to support municipalities in urban and rural areas to build new social infrastructure replacing the traditional long-stay residential institutions.

The project aims to change the philosophy of care for children with disabilities – the most vulnerable group of children in institutions – focusing on the prevention of risks for institutionalisation, support to families and provision of a family-based or family-like environment for each child placed in a specialised institution for children with disabilities.

The project seeks to provide children with an opportunity to access a package of services according to their individual needs. In this way, children will be provided with the opportunity to live in a family or a family-like environment, where a new approach to care will be applied. Currently, there are not enough services supporting children with disabilities in the community. At the same time, the existing services are not evenly distributed in accordance to the needs of the target groups. This is a barrier to prevention of abandonment and quality support for children with disabilities and their families. The project addresses this problem by planning a package of services in the community, which will provide a long-term alternative to children and families.

4. Further reading

- United Nation Convention on the rights of persons with disabilities. http://www.un.org/disabilities/convention/conventionfull.shtml
- Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions - European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe

  http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:EN:PDF
- Council Conclusion 6 June 2011on "The European pact of mental health and well-being : results and future action"
  http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/122389.pdf
- Mental health declaration of the European ministerial conference of the World Health Organisation of 15 January 2005.
  http://www.euro.who.int/__data/assets/pdf_file/0008/96452/E87301.pdf
- United Nation Convention on the rights of the child adopted in 1989
  http://www.unicef.org/crc/
- United Nations guidelines on the alternative care for children, adopted in 2009
  http://www.iss-ssi.org/2009/index.php?id=25
- Commission Recommendation of 20.2.2013 - Investing in children: breaking the cycle of disadvantage
  http://ec.europa.eu/social/BlobServlet?docId=9762&langId=en
- Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care
  www.deinstitutionalisationguide.eu