

MAKING COMMUNITY-BASED SERVICES A REALITY

Roadmap on deinstitutionalisation

5.12.13



SERVICE FOUNDATION
FOR PEOPLE WITH
AN INTELLECTUAL DISABILITY



IMPROVING SERVICES
IMPROVING LIVES

Introduction

EASPD is the European Association of Service providers for Persons with Disabilities. Its main objective is to put forward the rights of persons with disabilities by promoting the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) through effective and high quality services.

Since the ratification by Member States and the conclusion by the European Union of the UN CRPD, a paradigm shift has occurred in terms of how society views people with disabilities, accompanied by a wider understanding of the adaptations which society must make in order to ensure that the rights of people with disabilities are vindicated. For service providers the requirements enunciated in the UN CRPD call for a re-shaping of how services are provided, the development of new services not currently available to meet new and changing needs and/or the integration in the services of a person centred, inclusive, participative and individualised approach, adopting the new social rights model of disability.

This paradigm shift therefore requires a movement away from a medically oriented model of care, where the person with a disability is viewed as a passive receiver of care or worse as a person who needs to be cured, towards a social rights model where individuals are supported to become active citizens making a contribution to their own communities like everybody else.

One of the areas requiring improvements and/or changes is the way provision of long term and/or intense care is provided to persons with disabilities. All over Europe services have been developed in a different way for historical, cultural, socio-economic and political reasons.

In some countries residential care for persons with disabilities has the primary objective of providing shelter and means for survival. Such services do not typically promote a social rights approach to disability which results in individuals being excluded from society. While in some cases the situation is particularly difficult and, even the provision of basic survival measures is threatened on a daily basis, in other cases the level of medical care is adequate and reaches a high quality, however, the lack of a participative, inclusive and person-centred approach prevents the full enjoyment of human rights by persons with disability.

In other countries, the system of care is much more oriented towards a balanced mixture of the medical model and the social model type of care as these services – in the course of time - have been able to take care of persons with disabilities in a more inclusive way.

The development of effective and person-centred support systems requires efforts at all levels of the planning, (re)shaping and development of services that pose inevitably huge challenges for all stakeholders involved in the process.

Taking account of these national differences EASPD strives to make sure that whether services and supports are delivered in older more traditional ways or newer more contemporary ways, all should apply a person-centred inclusive approach in order to fully adapt to the users' needs and preferences and to fully guarantee equal opportunities to

disadvantaged people. However, EASPD recognizes that the processes that lead to this transition might not be smooth and easy.

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Managing this transition contains many challenges and careful planning is required to avoid unintended harmful consequences and also to ensure that the transition processes are implemented in the most efficient and effective way. For example, it is imperative that in managing the transition process people with significant disabilities and complex needs are not left behind, which in turn only generates additional needs. Also adopting a person-centred approach will inevitably require services to develop innovative solutions, providing greater choice and control throughout life.

EASPD is committed to the values of freedom of choice, participation and inclusion in the community as well as to individualised and person-centred approach in services.

EASPD is committed to raising awareness on the topic by promoting the exchange of information on the UN CRPD, exchanging and sharing models of good practice, informing its members on new developments in the sector and raising awareness at European and at national level on the topic.

In this regard, EASPD will monitor EU policies that are related to the topic, such as the European Disability Strategy, the Cohesion Policy¹, the EU Structural Funds and all the EU initiatives that will help to promote the rights of persons with disabilities in the field of residential care services.

¹ The Cohesion Policy seeks to strengthen the economic, social and territorial cohesion of the Union, improving the economic well-being and avoiding regional disparities. The European Commission has adopted a draft legislative package which will frame cohesion policy for 2014-2020. The new proposals are designed to reinforce the strategic dimension of the policy and to ensure that EU investment is targeted on Europe's long-term goals for growth and jobs ("Europe 2020").

1. Texts of reference

UN CRPD and community based living

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While the Convention elaborates on a number of issues in all areas of life, some concepts are underpinning its rationale and are therefore key in interpreting the text as they are cross-referenced in the entire text and set the basis for building a society free of stigma and hence of discrimination: inclusion, participation and community living.

Community based living is demanded in Article 19 and Article 23, 24 and 26. Community living translates also into participation in society.

Article 19 of the UN CRPD

Article 19 imposes a general obligation on Parties to enable persons with disabilities to live independently and to fully participate in all aspects of life. It recognizes the right of persons with disabilities to live independently and to be included in the community, thus it demands accommodation options equal to others, and it requires them to support the inclusion and participation of persons with disabilities in community life.

Article 19 of the UN Convention on the Rights of Persons with Disabilities clearly addresses the DI process, stating that persons with disabilities have the right to choose their place of residence and the right to live in the community, with freedom of choice equal to others.

This includes giving people with disabilities an opportunity to choose where and with whom they would like to live on an equal basis with others, and not obliging them to live in a particular living arrangement. It further includes an obligation to provide people with disabilities with access “to a range of in-home, residential and other community support services, including personal assistance”. It is clear that this excludes institutional care because services provided must support “living and inclusion in community” and prevent “isolation or segregation from the community”. Finally, States should ensure people with disabilities have access to mainstream services which have to be “responsive to their needs”.

Community based services

In the Common European guidelines on the transition from institutional to community-based care², 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 as opposed to an institution. 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 personal assistance for persons with disabilities, respite care and others. 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.

Segregation and institutions

The European Coalition for Community Living defines an institution as “any place in which people who have been labelled as having a disability care are isolated, segregated and/or

² Common European guidelines on the transition from institutional to community-based care. European Expert Group on the transition from institutional to community-based care, November 2012

compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size”. The Ad Hoc Expert Group on the Transition from Institutional to Community-based Care describes users as included in these institutions as “isolated from the broader community and/or compelled to live together; these users do not have sufficient control over their lives and over decisions which affect them; the requirements of the organization itself tend to take precedence over the users' individualized needs”.

2. Actions to be taken by EASPD

At political level

- Highlight the provisions of the UN CRPD concerning DI and CBS (in particular Article 19) in all relevant discussions and lobby activities at EU level.
- Promote a steady flow of information on DI and CBS between the EU level and the grassroots level.
- Continue to lobby and carry out awareness raising activities and research work within the European Expert Group on the transition from institutional to community-based services.
- Engage with trade unions through the European social dialogue to promote the DI process (when it comes to e.g. staff relocations and staff (re)training).
- Promote networking between mainstream and specialised providers seeking stronger cooperation at EU level.
- Raise awareness within the European institutions about the right to live independently in the community and the need to develop community-based services - including residential services - by ensuring that new legislation promotes the use of funding for services that are in line with the principles of participation, inclusion and individualised, quality and persons-centred services.
- Ensure that services for people with disabilities and civil society are adequately represented in all political discussions concerning deinstitutionalisation.
- Promoting the representation of people with disabilities by themselves and by their representatives in all political discussions concerning deinstitutionalisation.

At national level

- Convey the synergy and the consensus gained at EU level on DI and CBS to the national level through the organization of e.g. provider fora and ad hoc events on DI and CBS.
- Promote the exchange of success stories and models of good practice regarding CBS.
- Facilitate the developments on DI processes in the countries represented in its membership.
- Provide support to EASPD members in pushing DI processes and community based planning forward.
- Promote and work with inclusive evidenced-based research.
- Adopt a systemic approach to DI and CBS with different roles for different stakeholders (e.g. participation planning for authorities).

3. Recommendations to EASPD members

At national level

- Highlight the provisions of the UN CRPD concerning DI and CBS (in particular Article 19) in all relevant discussions and lobby activities at national level.
- Promote the use of European Union Funds to support the DI process (see “Toolkit on the use of European Union funds for the transition from institutional to community-based care”) at national level and highlight in its context models of good practices concerning DI processes.

At local level

- Ensure from the very beginning of the planning process a full participation of persons with disabilities in the shaping and the development of services for them. Universal design should be included in the service design.
- 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.
- Innovation in service provision should be fostered through structural involvement of persons with disabilities and their families.
- Self-advocacy activities should be promoted and supported.
- The new philosophy of social service provision, compliant with the UN CRPD, should be promoted through ad-hoc trainings to all professionals involved in the DI and CBS processes.
- Ensure good cooperation and coordination between health and social services and between professional and non-professional carers.
- Training programmes of future social, educational and health workers should be adapted to the UN CRPD social model of disability.
- Cooperate with the European Expert Group on the transition from institutional to community-based services.
- Promote the exchange of success stories and models of good practice regarding CBS.

4. Recommendations to decision makers

Recommendations to EU institutions

- Clarification regarding the appropriate terminology to be used and the target group of the DI process is needed. More positive human rights based language and its interpretation should be developed: i.e. promotion of “community-based living” as alternative for “segregating models”.
- The EU should develop European quality standards based on the UN CRPD in the spectrum of social services.
- Improve the knowledge base on institutions and community based setting services by defining - together with EUROSTAT and in close cooperation with the Member States - a minimum data set for support services which would allow for the monitoring of progress in the closure of institutions and the development of services in the community and for a comparability of data across the EU. Statistics should be published on the progress achieved in each Member State in the transition from institutions to community-based alternatives.
- Ask the Fundamental Rights Agency for data collection, research and analysis within the framework of its mandate.
- Use research available at EU level to support and (re)structure policy planning.
- Fund research that will facilitate the transition from institutions to community-based services. This can include a study on how to support people with disabilities in the process of choosing their living arrangements as well as a legal analysis of Member State legislation which - directly as well as indirectly - promotes institutionalisation.
- Promote inclusive research through e.g. the new EC research programme Horizon 2020.
- Address the issue of institutional care and its reform in the context of enlargement, neighbourhood and development policies. Progress reports should be used to outline steps to be taken by candidate, potential candidate and third countries to encourage the development of community-based alternatives to institutions and social inclusion of older people, children, persons with mental health problems and persons with disabilities. In order to more effectively monitor the implementation of its recommendations, the Commission should work together with

disabled peoples' organisations in those countries. The Commission should make sure that EU funding in these countries will be earmarked to promote the development of community-based alternatives to institutions which are compliant with the UN CRPD.

- Present a European Commission Communication on the transition from institutional to community-based supports, including the Common Basic Principles to be implemented in the process of transition.

Recommendations to Member States

- Sustainable funding should be allocated to CBS during the transition from institutions to CBS and importantly after the transition process has been completed
- Coordination of different government departments and agencies involved in the transition process should be ensured. The successful implementation of reform plans 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.
- Methodologies for (local) participation planning should be made available.
- Promote, support and finance independent self-advocacy groups.
- Systematic support to informal carers (most importantly family carers) should be provided to ensure choice, quality of care and quality of life.
- When implementing the DI process, governments should always involve people with disabilities, their families and their representatives in all phases of the process and take into consideration their personal needs and wishes.
- 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 families and communities to facilitate full and effective inclusion of and participation by people with disabilities in their communities.
- There should be clear and unambiguous articulation of the new vision, the methodologies employed to manage the transitions including all incentivisation measures, financial and otherwise.

5. Specific recommendations concerning the DI and CBS for all stakeholders

Involvement of all actors

- Persons with disabilities, their representatives and their families should be involved in an effective and structured way in all decision making processes concerning deinstitutionalization and the development of services and safeguard mechanisms.
- Individuals with a disability should be at the centre of the process of assessment, planning and service delivery regarding their lives and should be supported to take this role. Moreover self-advocacy provisions along with independent advocacy movements should be supported and established.
- Other stakeholders, such as mainstream social support providers, trade unions and relevant authorities, should be involved and actively seek cooperation with persons with disabilities respecting their leading role.
- 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.

- People with disabilities should be supported to achieve full citizenship and enjoy their rights as citizens to the full. Education and awareness-raising campaigns to this extent should be promoted.

Planning and monitoring of DI

- Identify legislative and administrative rules that directly or indirectly support institutionalisation or block the transition to community-based services - and change them to support the delivery of quality services in the community.
- Relationships built by people with disabilities in institutions should be acknowledged and respected in managing the transition to community based services.
- Attention should be paid to people with significant disabilities and complex needs, minorities and vulnerable groups to ensure equal opportunities to all and prevent specific groups from being separated and treated unfairly.
- The same standards should be used and the same rights should be provided throughout the health system regardless of a person's mental health diagnosis. Mental health problems should not constitute the basis for discrimination.
- Health care should be guaranteed when moving from institutions to community based services.
- Communication tools, with appropriate adaptations if needed, should be made available to users, facilitating full and effective integration and participation in the community.

Staff training and staff development

- Promote improved working conditions of professional carers, aiming to make the jobs in the sector attractive. Make it a requirement that bodies representing, training and accrediting the professional practice of staff working with older people, children and persons with disabilities adopt a commitment to supporting the human dignity, inclusion and autonomy of service users in their work. Ensure that staff training and accreditation include service users and are based on the principle of inclusion.
- Promote common guidelines regarding human resource management, the links to the local community and the full participation of persons with disabilities and their families in the development of services.
- Staff should be (re)trained based on the principles enshrined in UNCRPD of participation, inclusion, quality and person centred services.
- Responsive and effective quality community based services (CBS) depend on a flexible and well trained workforce. 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.
- Medication should only be used – if needed - with appropriate supervision – if the person cannot take care of it by himself- with regular review and with the informed consent of the person. Medication should not be used as an instrument of control.

Quality of Services

- Networking amongst providers and between mainstream and specialized providers should be part of the QAS and monitoring mechanism.
- 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. Quality assurance systems should address this issue.
- In some countries services and supports 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 those 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. Market oriented service development, if not managed properly with robust measures to ensure quality and safety often implemented through procurement procedures, can have a negative impact on the quality of the support provided. Equality and personalisation should be the focus of the development of community based services, not profit making.

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- 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 embedded.

6. Conclusions

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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 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 persons 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. Training of staff according to the principles enshrined in the UN CRPD is key in this regard.

Many countries have embarked on the process of transforming the way they provide care and support to children and adults by replacing long-stay institutional services with family - and community-based services. A key challenge is ensuring that the process of deinstitutionalisation itself is carried out in a way that respects the rights of persons with disabilities, includes appropriate safeguards and ensures community inclusion and participation for all individuals involved. The process needs to ensure that the new systems of care and support respect the rights, dignity, needs and wishes of each individual and their family.

This position paper was approved by the Board of EASPD in Brussels on the 5th of December 2013. This document will be reviewed in 2017.

7. References

Common European guidelines on the transition from institutional to community-based care. European Expert Group on the transition from institutional to community-based care, November 2012

Deinstitutionalisation of services for people with disabilities in western European countries, October 2011

COFACE European Charter for Family Carers, 2011

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, November 2012

Report of the Ad-Hoc Expert Group on the transition from institutional to community-based care. European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, September 2009

United Nations Convention on the Rights of Persons with Disabilities, 2006