

Comments by the European DI Expert Group to the Hungarian National Implementation programme of moving from institutional placement to small group accommodation

Introduction:

- European De-Institutionalisation Expert Group (EDIEG) was asked by DG Regional Development's representatives of Hungarian geographical desk for an independent review of above-mentioned document. EDIEG is a group of European wide umbrella NGOs covering main stakeholders relevant to DI process. The Group consists actually from following organizations: AGE (European Older People's Platform), COFACE (Confederation of Family Organisations in the EU), EASPD (European Association of Service Providers for Persons with Disabilities), ECCL (European Coalition for Community Living), EDF (European Disability Forum), Inclusion Europe, Mental Health Europe, Eurochild and Lumos. All mentioned organizations were involved into the process of providing their recommendations to the Hungarian program.

General comments:

- The Group would like to congratulate the Hungarian government on starting the process of transformation of institutional services to community-based care and support system.
- We see the document "Implementation programme of moving from institutional placement to small group accommodation" as a working paper. Based on this, a further more detailed DI strategy plan should be elaborated to include more clear figures, costs, and deadlines. We see the document as good background material for further national wide, transparent and opened discussion.
- If the process of reform will be carried out based only on the plans and principles described in the above-mentioned document, it will bare three main risks:

- 1. Over-investment in current institutional arrangements.**
- 2. Risk of maintaining parallel services.**
- 3. Too "institutional" alternatives.**

- We know similar risk scenarios that happened in many countries and places, which already have shifted, or are shifting from institutional to community-based services. There is already lot of knowledge on how to design and coordinate all processes of DI and not to replicate the "mistakes" of other such processes. To avoid these risks we put together a set of recommendations. We hope that our comments will be understood as constructive way of support and will lead to further dialogue and development of a long-term action plan.

Structure of the comments

- As mentioned above, several principles are not enough stressed in the content of the document itself. To start a process of DI without including them will lead to certain risks. A short description of the risks is presented in the first chapter.
- In the second chapter we address few key aspects of de-institutionalisation process and present the set of comments from our members organizations for each of them.
- The last chapter contains a summary of our review transposed into short and hopefully clear recommendations.

I. Risks:

1. Over-investment in current institutional arrangements

- A common response to poor quality care in institutions is to improve the physical conditions of the buildings in which these services are delivered. However, this often makes it more difficult to close institutions in the medium term, as authorities are reluctant to close a service where a great deal of money has been invested. Funds from external donors are frequently used in this way.
- To avoid this scenario a rule of "no investment" to already existing and not satisfactory institution has to be in place.

2. Risk of maintaining parallel services

- If the build-up of alternatives is not associated with progressive closure of existing institutions, it might result in a situation where the new community-based services function in parallel with the pre-existing institution(s). Such a two-tier system would likely be unsustainable in the long run - and particularly in times of crisis or of reduced budgets, the authorities might prefer to abolish the new service rather than the old and established one. In fact, the continued functioning of the pre-existing institution might be used as an argument to prove that de-institutionalisation as such has failed because it did not automatically reduce the number of beds in the institutional setting.
- Another risk of this scenario is when a part of the users remain in institutional care without tangible improvement of their condition, which is in itself unsatisfactory. Moreover, this may result in risks of leaving people with severe disabilities and/or complex needs behind. There is a tendency to “do the easy thing first” when it comes to de-institutionalisation projects.
- These risks must be avoided by including people with severe disabilities and complex needs from the beginning fully in any de-institutionalisation effort. It is also important to have a general plan of transforming- closing down original institution in total.

3. Too "institutional" alternatives

- Even where alternatives are set up and the pre-existing institution is being downsized and/or closed, the character of these alternatives might be problematic, because they are themselves too "institutional", not based on each individual's needs and preferences, which in turn is often due to insufficient involvement of users (and, where relevant, their families) in the planning, management and evaluation of services.
- Alternatives of inadequate size. Due to a lack of understanding of what community-based services are, there are cases of so-called de-institutionalisation policies wherein the "alternatives" are too similar to the institutional model.
- Alternatives which perpetuate institutional culture. Even where the alternative facilities are or appear small, they might be insufficiently different from the pre-existing establishment. Sometimes new services are set up in the vicinity of the original institution, just to ensure the staff and buildings are reused. Sometimes even the same building is offered as the alternative following an internal re-organisation to so-called "family-style" apartments. The result is that whilst physical conditions improve a little, users continue to live in the same isolated conditions.
- Alternatives with prevailing institutional culture. This risk is present in both of the above - particularly when the reform is reduced to change of housing as such without deliberate attention to re-training of staff with the intention to change the institutional culture.

II. Comments on key aspects of de-institutionalization process:

1. Full respect of the rights of the clients:

- *Disabled people should be involved in the design and furnishing of their apartments. Disabled people should be allowed to choose persons (friends or common-law partner) to live with.*
- The development of individual future plans (per person) should be integrated in the plan. Individual needs assessment (of the person living in the community) should be part of the strategy and lead to the provision of the support needed, not the other way around. A “human rights” driven system should be developed.
- Guardianship system needs to be replaced with a framework which will support disabled people to make their decision to the maximum of their capacity, and promote choice and control of disabled people over their lives, much more than just “to be allowed to choose a person to live with or to be involved in the design and furnishing of their apartments”.
- Work done by AGE through the project EUSTACEA and the Charter on the rights and

responsibilities of older people in need of long-term care can be taken as one of resources: <http://www.age-platform.eu/en/daphne>. A concrete toolkit is in preparation to help to implement the Charter.

2. Involvement of all stakeholders

- *Coordination of tasks can be carried out by establishing a National Coordination Body (NCB). It is important to involve families and civil organisations in the implementation in order to represent people with disabilities (including self-representation). Tasks and working rules of the Coordination Body should be defined.*
- The strategy should be discussed proactively with key stakeholders. It is important to make an effort to have as much as stakeholders on board to ensure ownership of the strategy. For sure disabled people, but as well specific groups like people with mental illnesses, older people, etc. Carers should be on board, both informal and professional. Local and regional authorities and representatives of the payers /social insurance, social security, etc.../ have to be on board to.
- The National Coordinating Body' activity should be uncompromisingly transparent. When implementing the DI in Hungary it is vital that experts are engaged in this process both in designing and monitoring the implementation. As part of this process the experts involved should include organisations/individuals who have had direct experience either living in institutions or having worked with them in trying to achieve change. It is important to involve families and civil organisations in the implementation in order to represent people with disabilities (including self-representation)".
- In order that the DI will work all stakeholders need to be signed up to it, as a piece of work which is co-produced in partnership on equal terms. This includes Government representatives, social care policy makers, local political and community representatives and most important user representative disability NGOs.
- While we appreciate the reference to consultation of families, it's crucial that family and civil organisations are involved not only in the implementation, but also in the elaboration and evaluation stages of the DI process. Their role is to remind that a preventive approach to institutionalisation is essential if we wish to cut the 'supply chain' of children with disabilities ending up in institutions.

3. The concept of 'Small Group homes and keeping institutions with max 50 residents

- The concept of 'Small Group homes is not the model of the future. It is a misleading & outdated model, which is not enabling people to live their own life, nor facilitates it empowering work by staff. The strategy should aim higher and go for 'Community based support systems'. The residential centers should accommodate 4 - 5 persons max (family size) or - better - be individual.
- To rent accommodations is mostly better then to build. Give more flexibility for clients to move on towards more independency.
- To keep existing institutions with reduced number of clients (max. 50) should not to be part of DI strategy. There Plans for full "transformation" of all institution have to be in place on the beginning.
- Good models on how to support persons with very complex needs that are available in the community exchange and learning across borders, should be considered for the strategy.

4. Use of remaining building

- *The functions of the remaining infrastructure should be reconsidered, filled with new content after the establishment of the small group homes.*
- It's important to ensure that there are no plans of the replacement of the existing clients population by another one (replace disabled people with older people, etc.).
- Concern "what will happen" with the buildings of original institution is very often a strong one and can be blocking real thinking in line of full community integration. The interest and needs of the clients has to be always a priority. Of course, the use of original building depends on its type, size, and location. But it is much better to consider selling the building or using it for fully different purpose.

5. Variety of community based services:

- *Service provider centres should be set up close to small group homes, which could provide comprehensive care including all levels from the basic services to professional care. Supporting in-house employment. Facilitating access to meaningful activities.*
- A range of available and affordable high-quality services in the community to replace institutional care needs to be built up. Support for support for family and informal carers (including respite services) should be provided.
- Capacity building in the community (mainstream) should be leading part of the strategy, better then developing " specialized centres" in the community
- As part of their caring role, family carers should benefit from the social rights and resources required to provide assistance to persons with disabilities and / or complex dependency needs in all daily activities and social life. Family carers have the right to enjoy equal treatment in terms of: ~~Labour~~ and employment : working time arrangements, holidays / leaves, return to work support, preservation of health and social protection schemes; ~~universal~~ access : transport, housing, culture, built environment, communication, etc., through financial compensation; ~~retirement~~ : through official recognition of their status as carers; ~~validation~~ of acquired skills : through official recognition of prior experience in their caring role".

More generally, COFACE advocates a recognition of the official status of family carers (see COFACE website, and in particular in our CHARTER FOR FAMILY CARERS (<http://coface-eu.org/en/upload/WG%20HANDICAP/Cha>

6. Funding and principles of its allocation.

- *Financial framework for small group homes and for utilization of abandoned infrastructure should be elaborated.*
- Adequate funding must be robustly in place and protected in order to develop and sustain DI in the development of community based services before process will start.
- There has to be a regulation that will allow clients a strong influence where money for their care go into. A principle "money follows the clients and not clients the money" has to be a leading one.
- System of money allocation has to be flexible not to block continuous change and development of a support and care system.
- All the additional costs of care must be refunded. The Luxembourgish "Loi assurance-dépendance" is often indicated as a good practice since it provides all persons needing care with a "dependency insurance", the amount varying by assessed levels of need. This can be used by the care-needer to pay formal or informal (= family) care.

7. Training, requalification and complex support of all formal and informal carers include professionals of existing institutions.

- *Staff of social institutions should be made interested in transforming the service system. Their skills should be developed in order to enable them to assist patients to their best knowledge also in the changed environment. Successful implementation needs prepared professionals. Trainings, programmes and campaigns are necessary for*

this. Representations of stakeholders concerned should be involved in establishing the new conditions.

- To give maximum support to the existing staff to be ready to work in a new way is essential. Re-training of professionals not to bring the institutional culture to the new services is a key issue. Detailed analysis skills and knowledge needed for new way of working has to be a first step.
- Continual supervision for the staff, especially in a time of changing all way of working has to be arranged.
- Full requalification for some of profession of institutions, which will be not needed or suitable for community setting, has to be available.
- Training and professional support of informal carers need to be developed.
- Clients and their family members have to be involved to a design as well delivery of all trainings.

8. Prevention of institutionalization:

We did not find in the plan any part dealing with the prevention of the new admissions to institutions

- As a general (although often forgotten) principle, we insist on prevention of institutionalization: holistic policies are necessary for the support of families and other informal carers as well as for strengthening the inclusive capacities of communities. Policies must meet families' needs in terms of resources, time and services.
- It is important to look to the whole environment meaning that if community-based services are provided and people can stay for longer at home, it is very important to look at what happens outside home: if the person cannot go outside because pavement are inadequate, public and private building services not accessible, there is no bank in the streets or in public parks (etc.), isolation will be still very high. One interesting programme to that regard is the WHO age-friendly cities programme (applicable as well in rural area, e.g. in Ireland they have age-friendly counties);[rteCOFACEHandicapEN.pdf](http://coface-handicap.eu.org/en/upload/WG%20HANDICAP/COFACEPosition-Respite-en.pdf));
- Flexible working time arrangements and various forms of leave must be introduced to allow parents of children with disabilities to engage in paid employment outside the home. Family carers must be allowed the time to take a break from their caring role (right to respite). More information on the right to respite: <http://coface-eu.org/en/upload/WG%20HANDICAP/COFACEPosition-Respite-en.pdf>.
- Regulation to stop any new admission to institutional care in the near future needs to be part of strategy.

9. Timing, planning and coordination of the process

- *Service planning strategies have to be modified in one year after the adoption of the program on de-institutionalisation. Preparing a 3-year National Action Plan (NAP) including a roadmap and professional content defined by the NCB. The NAP should incorporate proposals from the maintainers and representatives of other actors. The NAP can be implemented partly from EU resources.*
- It is essential that developing alternative community based services happens at the same time as DI to be sure that the community infrastructure is ready for the transition, and is securely in place with appropriate funding.
- Structures for comprehensive planning and coordination of the process have to be in place at all levels: governmental, regional as well as local.

10. Target groups

- *The programme targets groups according to disability types: sight and hearing-impaired persons, people with disabilities, persons with intellectual disabilities, persons with serious communication disabilities, autistic persons and persons with multiple disabilities.*
- People with psycho-social disabilities are (again) excluded from the plans. The plan has also to take into account older people with dementia diseases.
- While we completely understand that the Hungarian National Implementation Programme is designed for the above-mentioned target groups, the broader National DI strategy needs to include all target groups, children and people experiencing mental health issues as well.

11. System of quality control.

We did not find specific focus on quality control in the plan

- Standards of quality of care fully in line of UN Convention of the Rights of People with Disabilities have to be developed in the frame of national, transparent discussion.
- Systems of independent monitoring and quality control, based on above-mentioned standards, where users and their family members will be part of, need to be in place.

III. Summary of recommendations

- We recommend a revision of the plan and its principles, objectives and concrete steps in the frame of UN Convention of the Rights of People with Disabilities, with a particular focus on article 19. It is important that the plan will be based on the full respect of the principle of "Choice equal to others with whom to live, where to live".
- While we understand the National Implementation Programme is designed to cover the disability groups, the broader DI strategy needs to include all target groups, children and people experiencing mental health issues as well.
- A legal framework, which will support disabled people to make their decision to the maximum of their capacity, and promote choice and control of disabled people over their lives has to replace old "Guardianship system".
- The National Coordinating Body' activity should be uncompromisingly transparent. It is vital that experts are engaged in this process both in designing and monitoring the implementation.
- The Coordination body needs to be set on the level of responsible ministries. Transformational task forces need to support the reform on county level. National and regional body for the professional support of DI process is also beneficial. Openness and transparency of the process is highly required.
- Main emphasis has to be put on developing independent and supported living schemes with maximum use and inclusion to normal life. Small residential "group homes" facilities (max 4- 5 clients) have to be developed only for those who need intensive 24 hours support.
- The proper legal and financial framework should be elaborated not only for the model of care in small residential "group homes", but also for independent living and supported accommodation. The system of money allocation has to be flexible not to block continuous change and development of the support and care system. The principle "money follow the clients and not clients the money" has to be a leading one.
- Plans of full transition of each existing institution have to be considered from the beginning of the process. A plan for the remaining building cannot be based on the assumption of using the building for any other type of clients / residents.
- The framework for investment plans should to be based on needs and situation

assessment as well as complex regional DI strategy.

- A range of available and affordable high-quality services in the community to replace institutional care needs to be built up. Support for support for family and informal carers (including respite services) should be provided. Capacity building in the community (mainstream) should be leading part of the strategy, better then developing “ specialised centres” in the community. Regulation to stop any new admission to institutional care in a near future needs to be part of strategy.
- Trainings need to be accompanied by full requalification for some of professions of institutions, which will be not needed or suitable for community setting. Training and professional support of informal carers need to be available too. Clients and their family members have to be involved in the design as well delivery of the trainings.
- Standards of quality of care fully in line with the UN Convention of the Rights of People with Disabilities have to be developed and a system of its independent monitoring has to be on place before DI process starts.