

# 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





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## **Foreword**

*Across the European Union, many people spend long years in institutional care. Some of them have physical or intellectual disabilities, others suffer from mental health problems, and yet others are elderly and frail. There are also many children in institutions, both with disabilities and without.*

*For decades, the existence of such institutional care was seen as proof that society cares, that it does not leave vulnerable persons without assistance and that it provides the needy with food, shelter, clothing and treatment. But is this indeed the best possible model which advanced European societies can offer to these people in the 21st century? I am convinced that in an age when non-material aspects such as human dignity, autonomy and inclusion in the community are increasingly recognised as being of paramount importance, European societies should aim for more humane, person-centred, individualised models of care. The users themselves and, where applicable, also their families should become partners and take part in all decision-making. Everyone should be enabled to reach their full potential.*

*The European Commission has previously financed studies which provided comparisons between institutional and community-based care in terms of their quality and costs. The work of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care moves one step beyond them. It offers not merely well-argued rationale for change but also realistic advice on how to achieve it (and also what to avoid), distilled from the experience acquired in those Member States where such reforms have already been carried out. The analysis of key challenges, followed by a set of Common Basic Principles and concrete recommendations to Member States and the European Commission, can be seen as a "winning mix" of idealistic aims and concrete, pragmatic guidelines for their achievement.*

*The issues which are addressed in this report are inseparable from our joint European commitment to the values of fundamental rights and social inclusion. Therefore, I welcome the result of the Expert Group's work - a slender but weighty volume - and I hope that it will become a source of inspiration for policymakers in the Member States as well as on the European level.*



Vladimír Špidla

Commissioner for Employment, Social Affairs and Equal Opportunities

## **Executive summary**

Many people of all ages and different conditions (elderly, children, persons with disabilities – including persons with mental health problems) live in residential institutions which tend to segregate them from the community. For the purposes of this report, these institutions are not defined primarily by their size but above all by features of “institutional culture” (depersonalisation, rigidity of routine, block treatment, social distance, paternalism). Size is merely an indicator - the larger the setting, the fewer the chances are to guarantee individualised, needs-tailored services as well as participation and inclusion in the community.

The actual number of persons in institutional care is difficult to ascertain due to the lack of available data, but it is certainly in the millions. In some Member States institutional care still accounts for more than half of public care expenditure. This model predominates above all in Central and Eastern Europe. Due to population ageing, the numbers of persons requiring some form of long-term care are set to grow steadily over the next decades.

There is strong evidence in support of transition from institutional care to community-based alternatives (deinstitutionalisation). These can provide better results for users, their families and the staff while their costs are comparable to those of institutional care if the comparison is made on the basis of comparable needs of residents and comparable quality of care. The current economic crisis should thus not be seen as a reason to delay existing or planned processes of deinstitutionalisation. Costly improvements in the physical conditions of existing institutions, which are often proposed as a response to findings of substandard care, are also problematic because they fail to change the institutional culture and make it more difficult to close these institutions in the long term.

Several key challenges of deinstitutionalisation processes have been identified. These include the replication of institutional culture in community-based services and the long-term persistence of parallel services (failure to close the institution). Conversely, there is a risk of failure to create appropriate community-based services due to unrealistic targets and timetables which exceed the capacity for their development. This is particularly likely to happen when deinstitutionalisation is seen mainly as a cost-cutting exercise.

A set of Common Basic Principles has been drawn from best practices in this area as well as from the evaluation of key challenges mentioned above. In general, the process must respect users' rights, and users have to be involved in all decision-making processes. There has to be a holistic system of prevention of placement into institutions. Community-based services must be created in parallel with the closure of the institutions. The process requires sufficient and well-trained staff with skills appropriate for community-based care as well as adequate support to families. Both the transition process and the resulting services need quality control with a clear focus on user satisfaction. Continuous awareness-raising is necessary.

The report addresses recommendations to Member States which have the main responsibility for action in this area. They should guarantee that users are fully informed and actively involved in decision-making processes; review legislative and administrative rules which directly or indirectly support institutionalisation and change them; adopt strategies and action plans based on the Common Basic Principles; use EU Structural Funds for this purpose; establish systems of mandatory quality monitoring related to the quality of life of the users;

promote improved working conditions of professional carers and provide systematic support to informal ones etc. Last but not least, they should ensure vertical and horizontal coordination of different authorities and agencies involved in the transition process.

Finally, the report also makes recommendations to the European Commission, namely to present a Communication on the transition from institutional to community-based care; to build the Common Basic Principles into all the relevant EU policies; to provide guidelines on the use of EU Structural Funds and other funding instruments for deinstitutionalisation; to promote and facilitate exchange of models of good practice in this area; to establish a pool of independent experts on the issue; to improve the knowledge base by defining a minimum data set for residential services; to fund research in this area; to raise the issue of investing into community-based care in the debate on the future of Cohesion Policy after 2013; and to raise awareness of the issue within the Commission itself.

## **I. Conceptual framework**

### The right to live independently and to be included in the community

The European Union and its Member States are founded on the common values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights. All persons have the right to live independently and to be included in the community, the right to choose their place of residence and where and with whom they live, and the right to live in dignity. All children have a right to family life, whether their own family or a foster family (if they have no family or if they are at risk in their family). Those rights are set out in the relevant international (UN) and European human rights treaties, including the Convention on the Rights of Persons with Disabilities<sup>1</sup>, the Convention on the Rights of the Child, the revised European Social Charter<sup>2</sup> as well as in the Charter of Fundamental Rights of the European Union.

In practice, the right to live in the community requires the availability of community-based services which provide the support which people need and enable them to participate in everyday life. By contrast, long-term placement of persons in residential institutions can be seen as conflicting with their right to live in the community.

### Users of services

Legislative frameworks as well as academic research usually apply a separate approach to four categories of users of services - persons with disabilities, elderly people, children and persons with mental health problems. The purpose of this Report is to provide a cross-cutting approach, trying to highlight common features and approaches.

However, it is acknowledged that the proposed solutions need to be adapted to the different needs of the four categories. For instance, it is understood that children - both with and without disabilities - are particularly vulnerable to detrimental effects of institutionalisation because institutions do not provide an appropriate environment for their moral, psychological and emotional development.

### Definition of institutions

It is difficult to provide an all-encompassing definition of an "institution" or of "institutional care", mainly because of different cultural and legal frameworks in Member States. For instance, in some Member States even the providers of non-residential community-based services are classified as "institutions" because of the legal framework. For the purposes of this Report, however, we will understand "institutional care" as care provided in segregating residential institutions.

Some definitions of institutions are based on the number of places in a facility, e.g., defining an institution as a residential facility with 30 or more places. This definition can be useful when it comes to collecting data, describing trends and monitoring progress. However, an institution is not defined only by its size, which is just an indicator of more fundamental

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<sup>1</sup> See in particular Articles 12, 14, 15, 16, 17, 19, 23, 25, 26, 28.

<sup>2</sup> See in particular Articles 15, 17, 23.



characteristics which make a service "institutional". It does appear that the larger the setting, the fewer the chances are to guarantee individualised, needs-tailored services as well as participation and inclusion in the community. On the other hand, the reverse is not necessarily true (i.e., there can be small-scale facilities with a profoundly institutional character of care).

### Institutional culture

Rather than using any specific cut-off point for institution size, the Report will deal with "institutions" or "institutional care" from the perspective of **human rights and dignity of users, their quality of life and health, autonomy and social inclusion**. When speaking about "institutions", we will mean those residential care services which display an "institutional culture"; the external characteristics of the institutions - the buildings themselves - are regarded as being merely the most visible (but not necessarily the most important) among the defining phenomena.

Typical characteristics of "institutional culture" have been described and analysed by pioneering researchers some four decades ago. It has long been argued that institutional care segregates users and tends to be characterised by *depersonalisation* (removal of personal possessions, signs and symbols of individuality and humanity), *rigidity of routine* (fixed timetables for waking, eating and activity irrespective of personal preferences or needs), *block treatment* (processing people in groups without privacy or individuality) and *social distance* (symbolising the different status of staff and residents)<sup>3</sup>. Residents of such institutions develop passive ("institutionalised") behaviour in their adaptation to these routines, to boredom and to a lack of meaningful activities. Also the care workers - as Goffman famously described in the case of a mental health institution<sup>4</sup> - tend to become increasingly "institutionalised" over time.

Ultimately, the care practices reflect attitudes and beliefs which were deemed necessary for staff to hold in order to cope with the tasks set by the institution. The care ethic in residential institutions has traditionally been **paternalistic rather than interactive**. In many types of institutions (for persons with disabilities and those with mental health problems, but to some extent also in those for the elderly and for infants), the domination of medical professionals and health-care staff continues to maintain social distance between staff and users. The medical model of care carries the risk of reducing individuals to their diagnoses.

For the purposes of this Report, "institutional care" will thus be understood as any residential care where:

- users are 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 organisation itself tend to take precedence over the users' individualised needs<sup>5</sup>.

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<sup>3</sup> King, R. D., Raynes, N. V. and Tizard, J. (1971) *Patterns of residential care: Sociological studies in institutions for handicapped children*. London: Routledge and Kegan Paul.

<sup>4</sup> Goffman, E. (1968) *Asylums: essays on the social situation of mental patients and other inmates*. Harmondsworth: Penguin.

<sup>5</sup> The authors draw partly on the definition provided for one particular user group - persons with intellectual disabilities - by a Canadian activist organisation, People First: "An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated.

## II. Current situation in the EU

The most recent EU Joint Report on Social Protection and Social Inclusion<sup>6</sup> presented in 2009 highlights the need to reaffirm commitment to ensure universal access to high quality and affordable long-term care. Although most people who need support prefer to receive services at home or in a community-based setting rather than in an institution, in many countries institutional care still accounts for more than half of public care expenditure. While this pattern is most pronounced in countries of Central and Eastern Europe, the issue is by no means exclusive to them. In some EU Member States, excessively rigid legislative and administrative rules (e.g., on financing, security or hygiene) make it difficult to provide services in other settings than in large institutions.

The report of a study carried out in the EU Member States and Turkey, *De-institutionalisation and community living: outcomes and costs* (further "DECLOC")<sup>7</sup>, found that nearly 1.2 million disabled children and adults lived in long-stay residential institutions. Over a quarter of places in institutions are filled by people with intellectual disabilities, while people with mental health problems are the next most represented group. The total number of residents is likely to be even higher, as most Member States keep only partial data about the number of people in institutions. DECLOC found that in 16 out of 25 countries for which information was available, state funds (local or regional) are used at least in part to support institutions of more than 100 places. In 21 countries state funds are used to support institutions of more than 30 places.

In the area of mental health, there has been a marked decrease in long-term institutional care over the last few decades. This trend has been part of a general reduction of the number of psychiatric hospital beds, as demonstrated by the MHEEN II report<sup>8</sup>. However, the extent of these changes varies considerably, being far more pronounced in Western Europe than in Central and Eastern Europe.

As for children, across the EU there are estimated<sup>9</sup> to be 150,000 children living in residential care settings, including 'special schools', infant homes, homes for mentally or physically disabled, homes for children with behavioural problems, institutions for young offenders, after-care homes. In most Western European countries, most children in public care are placed within family-based settings – either in kinship or foster care families. This is not the case in Central and Eastern Europe, where residential-care settings still predominate.

However, the above quoted data remain partial and fragmented, which means that a comprehensive picture cannot be drawn at present.

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An institution is any place where 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."

<sup>6</sup> [http://ec.europa.eu/employment\\_social/spsi/joint\\_reports\\_en.htm#2009](http://ec.europa.eu/employment_social/spsi/joint_reports_en.htm#2009)

<sup>7</sup> Mansell J., Knapp M., Beadle-Brown J., and Beecham J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent

<sup>8</sup> Medeiros H., McDaid D., Knapp M., and the MHEEN Group (2008) *Shifting care from hospital to the community in Europe: Economic challenges and opportunities*.

<sup>9</sup> According to a recent compilation of national surveys on the situation across the EU by EUROCHILD, [http://www.eurochild.org/index.php?id=208&tx\\_ttnews\[tt\\_news\]=271&tx\\_ttnews\[backPid\]=185&cHash=92a7bc14dc](http://www.eurochild.org/index.php?id=208&tx_ttnews[tt_news]=271&tx_ttnews[backPid]=185&cHash=92a7bc14dc)

### **III. The case for transition from institutional to community-based care**

#### Material and non-material aspects of institutional care

Material conditions of life in institutions tend to be worse than for most people in the wider society. Moreover, the four "classical" characteristics - depersonalisation, rigidity of routine, block treatment and social distance - are often particularly pronounced where the material conditions are poor: if the management struggles to secure food, heating and other fundamentals, it leaves little room for therapy or meaningful activities. Extreme cases of material deprivation combined with neglect and/or abusive practices have recently been documented, above all in some "new" Member States, but also in "old" ones.

However, the problematic characteristics of institutional care are not exclusively linked to poor material conditions - and it is doubtful that they could be solved simply by an improvement thereof. It is obvious that better staff-user ratios and increased emphasis on meaningful activities can improve the quality of care. Nonetheless, problems linked to depersonalisation, block treatment, rigid routines and social distance continue to exist also in establishments where the overall material conditions are reasonably good.

In addition, some of the defining characteristics of institutions are increasingly recognised as stigmatising users who are physically and socially isolated (segregated) from the wider society. Whether by policy or for want of alternative sources of support, most residents are not easily able to leave them to live elsewhere. This, again, appears to be an inherent problem of institutional care which cannot be solved by increasing expenditure on institutions.

Contemporary institutions vary greatly in quality between Member States as well within a particular country in terms of size, material conditions and care practices. Consequently, these institutions manifest the aforementioned characteristics in differing degrees. However, it can be argued that some problems remain in principle inherent to the institutional set-up as such. Available research is quite heavily focused on English-speaking countries, but a recent study<sup>10</sup> of institutions in France, Hungary, Poland and Romania showed that although there were differences between institutions in these respective Member States countries, they provided similarly poor outcomes for residents as institutions studied in the United Kingdom, USA and Sweden in the 1970s.

Therefore, the institutional model of care is increasingly seen as inadequate. There is a growing recognition - though perhaps falling short of a clear consensus - that no matter how much money is spent on institutions, the characteristics of institutional care are bound to make it extremely difficult to provide adequate quality of life for users, to ensure enjoyment of human rights and accomplish the goal of social inclusion.

#### Institutional care vs. community living

While in some Member States or their regions the pre-existing large institutions were mostly replaced by smaller ones, elsewhere genuine deinstitutionalisation has occurred, gradually

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<sup>10</sup> Freyhoff G, Parker C, Coué M, Greig N. (2004) *Included in Society: Results and recommendations of the European research initiative on community-based residential alternatives for disabled people*. Brussels: Inclusion Europe.

replacing the large institutions by support services in the community (community care, home care). Pioneers of deinstitutionalisation include Sweden and the United Kingdom as well as non-EU countries such as Norway or the USA.

Evidence from research and evaluation of alternatives to institutional care supports the transition to community-based services<sup>11</sup>. A large number of research studies overwhelmingly show better results for people receiving services, their families and the staff supporting them.

A review of 73 studies of deinstitutionalisation and community living carried out in the mid-1990s<sup>12</sup> illustrated the variation between services on a range of different measures. Their data showed that **the ranges of scores on different measures overlapped considerably between large institutions, small institutions and community-based services. On average, community-based services appeared to be the best option.** In evaluating the effect of moving from institutional to community services in the United Kingdom and Ireland, the majority of studies reported positive effects in five of six areas (competence and personal growth, observed challenging behaviour, community participation, engagement in meaningful activity and contact from staff); only in one area (reported challenging behaviour) did the majority of studies report no change. Similar (though slightly less clear-cut) results have been produced by studies from the USA and Australia.

In general, available studies confirm that **if high-quality community services are provided, most formerly institutionalised users have a clear preference for community living and display higher levels of personal satisfaction and social inclusion**, with fewer problems linked to insecurity or loneliness than anticipated. *Included in Society*, a study with recommendations funded by the European Commission which described general problems of institutional care as well as success stories concerning deinstitutionalisation, concluded that "on average, community-based services offer better outcomes in terms of quality of life for disabled people than do institutions", while admitting that the replacement of institutions by community-based alternatives does not in itself guarantee better outcomes ("it is a necessary but not sufficient condition").

The most clear-cut differences in outcomes can be demonstrated in the area of care for children (disabled as well as non-disabled). It is well documented that children who grow up in institutions display appalling rates of failure in subsequent adult life (alcoholism and drug dependency, criminal behaviour, suicide). By contrast, young adults who grew up in foster care tend to integrate into society without appreciable difficulties. There is now increasing evidence<sup>13</sup> that the effects of institutionalisation for children - even where the institutions in question have good material conditions and qualified staff<sup>14</sup> - can include poor physical health, severe developmental delays, (further) disability, and potentially irreversible psychological damage.

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<sup>11</sup> DECLOC report

<sup>12</sup> Emerson, E. and Hatton, C. (1994) *Moving Out: Relocation from Hospital to Community*. London: Her Majesty's Stationery Office.

<sup>13</sup> United Nations Secretary-General's Study on Violence against Children (2006) *The World Report on Violence against Children*, p. 189.

<sup>14</sup> A typical example is that of the infant care institutions in some "new" Member States which tend to be run by the respective health ministries. Their problem lies neither in material deficiencies nor in the absence of medical staff, but in the strictly medical model of care which does not provide the infants with sensory and emotional stimulation necessary for healthy development.

### Congregate vs. dispersed housing

Village-type settings (congregate or cluster housing) can be regarded as a transitional form between institutional and community-based care. They may provide some benefits for a population with a lower level of support needs and, where they exist, they may become an important part of the spectrum of service provision but they are only ever likely to occupy a niche in the market for care.

A recent review of congregate housing compared with dispersed housing in the community<sup>15</sup> showed that dispersed housing was superior to cluster housing on the majority of quality indicators studied.

### The cost-outcome ratio

For policymakers, the outcomes of institutional and community-based care are inevitably dealt with in the context of costs. The complexities of the relationship between needs, costs and outcomes were dealt with most extensively in the DECLOC report. The dominant findings was that there is no evidence that community-based models of care are inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and comparable quality of care. Other studies argue that residential care may in fact be more expensive than community care<sup>16</sup>, but the assessment of all direct and indirect costs - and of long-term benefits of increased social participation - remains open to different interpretations.

Some policymakers whose concerns are strictly economic (particularly in the context of the current economic crisis, *see following paragraph*) might nonetheless find reassurance in the finding that low-quality institutional care can be cheaper than good community care which provides better outcomes. The authors of this report believe, however, that such reasoning would be deeply flawed. Preserving low-cost institutional care of low quality is not an ethically acceptable option and it is not sustainable in pragmatic terms either. Sooner or later, public pressure is likely to result in improving the quality of care in those institutions where it has traditionally been poor - and at that stage, community care is likely to provide an option which will be not only intrinsically better for the user, but also cost-effective from the perspective of the provider.

### Context of the current economic crisis

The aforementioned dilemmas of costs and outcome are put into a new perspective by recent development. The economic crisis carries a very real risk that governments (public authorities) will be tempted to preserve their budget balance by reducing expenditure on social services, the greatest part of which is represented by staff costs. As a result, staff in care settings of whichever kind (institutional as well as community-based) could be at increased

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<sup>15</sup> Mansell, J., and Beadle-Brown, J. (submitted)

<sup>16</sup> Ward, H., Holmes, L. and Soper, J. (2008) *Costs and Consequences of Placing Children in Care*. London: Jessica Kingsley Publishers. The study claimed that the average unit cost for maintaining a child for a week in a residential placement was 4.5 times that of an independent living arrangement, 8 times that of the cost for foster care, 9.5 times that of a placement with family and friends, and more than 12.5 times that of a placement with own parents.

risk of layoffs, while the quality of care for users could be threatened by generalised cost-cutting and a reduced staff-user ratio.

From the perspective of the likely development of the care sector, such decisions by the authorities appear short-sighted. Not only is it ethically unacceptable to undermine those standards of care which have already been achieved (and which are often still far from ideal), but it is also in marked contrast to the expected demographic trends and their implications. The care sector is one of the few which is not likely to experience a decrease in demand in the future - quite on the contrary, due to population ageing, the numbers of persons requiring some form of long term care are set to grow steadily over the next decades. Generalised cost-cutting in the care sector and layoffs of qualified staff are therefore to be seen as deeply counterproductive in the long run because they carry the risk that qualified staff will move to other sectors, thus making future needs more difficult to meet.

Obviously, the economic crisis cannot be ignored. But to put the reform process properly into the context of the economic crisis, it appears necessary to look at the crisis as an opportunity and not as an excuse to delay existing or planned processes of transition from institutional to community-based care.

## **IV. Key challenges in transition from institutional to community-based care and suggestions on how to address them**

The major changes required to move from a system that relies on residential institutions to one which provides diversified community-based services impact upon a wide range of people. Without proper planning and preparation, the rights and interests of the users involved may become forgotten among other concerns of local communities, institution personnel and local politicians.

### **1. Over-investment in current institutional arrangements**

This is a common reaction to emergencies - mostly to situations where extremes of very poor quality of care and/or abuse are "discovered" (or, rather, reported by human rights watchdogs and investigative journalists). While such intolerable situations require immediate attention, there is a risk that isolated focus on these extremes might detract from attention to necessary systemic changes:

Over-investment in buildings. A common response to poor quality care in institutions is to improve the physical conditions. 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.

This issue goes beyond that of remedying obvious extremes. Even care of average quality can be subject to initiatives which aim to improve the material standard (through investment in the physical environment), the staff-to-user ratio or other parameters. While such changes can in some instances ameliorate the quality of life of users, often such investment represents a missed opportunity for more systemic change, as it then becomes more difficult to advocate closure and systemic reform.

Exclusive focus on failure of individuals. Obviously, it is necessary to promote personal responsibility of individual staff members (and in particular, management). In cases of particularly unacceptable conditions and human rights abuses, those responsible should be clearly identified and, where applicable, prosecuted. However, it would be erroneous to focus only on individual failures and overlook the systemic issues at stake. In fact, many staff members who have been part of clearly unsatisfactory practices can be re-trained to provide services of much better quality in a different setting.

### **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 wherein the new community-based services function in parallel with the pre-existing institution(s). 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 the following risks:

Leaving people with severe disabilities and/or complex needs behind. There is a tendency to "do the easy thing first" when it comes to deinstitutionalisation projects. People with light or

moderate levels of disability are moved into community-based services in a gradual approach to close down large residential institutions. In many situations, these people have been supporting the staff of the residential institution in caring for more severely disabled people. De-institutionalising higher functioning people first thus leads to a situation where the remaining staff is left with a number of very severely disabled people for whom it will be difficult to find places in the new community-based system that is focused only on the needs of people with lesser disabilities. These risks must be avoided by including people with severe disabilities and complex needs from the beginning fully in any deinstitutionalisation effort.

Generating ("over-meeting") additional needs. If there is insufficient transfer of users from institutional care into the new services, it is very likely (as examples from the USA have shown) that these new services will try to absorb other potential users who may have initially had little need for them, in order to justify their existence. Conversely, even if the users are being transferred but the places in the pre-existing institutions stay, there is a natural inclination for these institutions to "suck in" other potential users, even from other user groups than originally intended.

Creating long-term double expenses. Moreover, there is a risk of "double expenses" for the two systems which operate in parallel. It needs to be acknowledged that there will be a need for both 'hump' costs – initial investment in the new community facilities to get them underway – as well as double running costs to resource both the old and the new services in parallel **for a few years until the institution has fully closed down**. These costs have to be built into the budgets accompanying deinstitutionalisation strategies. However, this should **not lead to a long-term situation where both services exist in parallel indefinitely**. 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 deinstitutionalisation as such has failed because it did not automatically reduce the number of beds in the institutional setting.

### **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 deinstitutionalisation policies wherein the "alternatives" are too similar to the institutional model. This might be due to their size - indeed, in some countries even quite large residential institutions (with up to 80 residents) may be the end result of dismantling of larger institutions.

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



environment and little is done to reintegrate them in the community or to prevent further admissions.

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.

#### **4. Closure without adequate alternatives**

In some countries, government strategies for deinstitutionalisation set arbitrary targets such as '50% reduction of users in institutions in a five year period'. Such targets are rarely calculated based on the capacity of the government and local authorities to develop appropriate alternative services in that period of time. Often they are seen rather as a cost-cutting exercise: once authorities realise that non-institutional placements are cheaper, institutions are closed in order to save money.

Unrealistic deadlines may also be set by external donors, forcing a too rapid deinstitutionalisation or an incomplete process. This can result in harm to users if they are not prepared for moving or if their new placements have been insufficiently prepared.

Whether stemming from a bureaucratic approach, from cost-cutting demands or from external donors' pressure, poorly implemented deinstitutionalisation policies can result in inappropriate measures being taken in order to meet the target. They are associated with the following risks:

Lack of available and affordable alternatives of appropriate quality. Where arbitrary targets and unrealistic deadlines are in place (and where the driving force is an intention to cut costs), sufficient finances are often not available to carry out the process in a way that ensures that each individual user receives adequate services. It has to be remembered that while community-based care for most users is likely to be cheaper than care in a residential institution, there are categories of users who will require extensive support that will be more costly (e.g., 24 hour personal assistance). If such services are not developed because the emphasis is on cost-cutting, such users might in fact experience a setback in the institutional reform process. Implementation of schemes supporting family carers is also indispensable to avoid such a setback.

Taking the easy way out. One result of arbitrary targets is that they create a focus on moving the users who are 'easiest to place' into the community and reducing overall numbers in institutions (see above). This strategy often leaves behind users with the highest support needs, such as those with severe disabilities (although these users with most complex needs should have been prioritised in the deinstitutionalisation process).

Purely administrative "solutions". To fulfil arbitrary targets and/or save costs, local authorities often take the decision to merge institutions where numbers have reduced. This can result in users being moved from one inadequate institutional placement to another, traumatising them in the process. For instance children with severe disabilities may even die of shock as a result of such an abrupt move. Mergers or amalgamation of institutions can also result in inappropriate groupings of users (for example, young babies placed together with older children who display challenging behaviour), thus increasing the risk of harm and abuse.

The risk of the fourth type has been demonstrated particularly in the hasty and unprepared deinstitutionalisation processes in the area of mental health care in several countries from the 1970s onwards<sup>17</sup>. Although these processes eventually did bring a number of positive developments, providing better of life for many former residents, they also suffered from insufficient parallel development of alternatives (at least in the initial stage) which resulted in a real lack of access to services for the users.

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<sup>17</sup> Such ambiguous results were reported from deinstitutionalisation processes in countries such as Italy, United Kingdom and the USA (New York State).

## **V. Common Basic Principles for transition from institutional to community-based care**

A set of Common Basic Principles has been drawn from best practices in the transition from institutional to community-based care<sup>18</sup> as well as from the evaluation of the key challenges mentioned above:

1. Respecting users' rights and involving them in decision-making: Users (and their families) should be full partners in the transition process. They should be actively involved and consulted in the development, delivery and evaluation of the services they receive. Users need to be provided with appropriate information in a manner which they can understand. Where necessary, they should have support in decision-making through a person of their choice. The specific needs and requirements of each individual should be respected. As regards children, all placements should be made in the best interest of the child.
2. Prevention of institutionalisation: The necessary steps should be taken to prevent the placement of individuals into institutions<sup>19</sup>. Holistic policies are necessary for the support of families and other informal carers as well as for strengthening the inclusive capacities of communities.
3. Creation of community-based services: A range of available and affordable high-quality services in the community to replace institutional care needs to be built up. These services should start from the needs and personal preferences of individual users. They should provide support for family and informal carers. Their purpose is to prevent further admissions to institutional care, to provide placements for the persons currently in institutions and also to benefit those people who live in the community (with their families or otherwise), but without adequate support.
4. Closure of institutions: This process should, if possible, start from pilot projects. Planning should include the preparation of an individual plan for each user and the assessment of the training needs of staff wishing to work in the community. There should be a proper preparation for users to minimise the risks of a trauma linked to a change in their living settings. Institutions should be closed down in a way which ensures that no users are left behind in unsuitable conditions. Those with highest support needs should be given priority (e.g., babies, children and adults with severe disabilities and those in institutions with very poor physical conditions and/or abusive regimes).
5. Restriction on investment in existing institutions: Processes of transition from institutional to community-based care typically take many years. Meanwhile, many users live in unsuitable and unsanitary conditions. Therefore some renovation of existing institutions may be required. However, this should be limited to investment which is strictly necessary

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<sup>18</sup> See the DECLOC report and the Second Disability High Level Group Report on Implementation of the UN Convention on the Rights of Persons with Disabilities (2009), <http://ec.europa.eu/social/BlobServlet?docId=2790&langId=en>

<sup>19</sup> In some instances this is not desirable due to risk of harm - e.g., children or elderly persons who have been abused or are at a high risk of abuse in domestic settings. For children, the next best alternative is substitute family care (foster care and adoption, where appropriate) and only when these alternatives are not possible should residential options be explored.

to ensure adequate sanitation, water and heating. Too much investment in a building is likely to make it difficult to close the facility later on.

6. Development of human resources: It is vital to ensure the availability of sufficient and well-trained staff with skills appropriate for community-based care, which is based on partnership, inclusive attitudes and an inter-disciplinary approach. This may involve re-training and re-qualification of staff who previously worked within the institutional culture. By redeploying the personnel who can be trained to work in the community, resistance to the process of reform can be reduced. It is desirable that representatives of the user group are involved as trainers in the initial qualification and the re-qualification of staff at all levels. Also family carers should have access to training programmes aimed at improving the quality of their care giving.
7. Efficient use of resources: The current institutional system involves a huge resource commitment – budgets, buildings and equipment. As far as is possible, and in the best interests of users, these resources should be transferred from the existing institution to new services. Re-use of existing resources ensures that the reform process is less expensive and more sustainable. Budgets for running costs can be transferred to cover the costs of running services in the community, such as small group homes and family support centres; at times, buildings can be reused for other purposes (where they are appropriately located and in sufficiently good condition).
8. Control of quality: Systems of quality control should concern both the process of transition and the resulting services, with a clear focus on user satisfaction. The involvement of users, their families and their representative organisations in the monitoring of quality is crucial
9. Holistic approach: Issues concerning transition from institutional to community-based care must be addressed across all the relevant policy areas, such as employment, education, health, social policy and others. Such a holistic approach should guarantee coordination and policy consistency across different branches of government as well as continuity of care, e.g., between childhood and adulthood<sup>20</sup>.
10. Continuous awareness-raising: The transformation process needs to be accompanied by efforts to ensure that key professional bodies support it in terms of the values which they transmit to their current and potential members, as well as to the society at large. Simultaneously, the awareness of non-professional decision-makers and opinion-makers and of the broader public should be raised in order to ensure the consistency of their attitudes with the desired values. Particular attention needs to be paid to the development of inclusive attitudes in local communities in places where the services are to function.

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This applies particularly to individuals with more complex needs.

## VI. Recommendations

While addressing the issues of institutional care reform, both the Member States and the EU institutions should respect and enforce the rights and the principles set by the **Charter of Fundamental Rights of the European Union**. Moreover, due attention must be paid to the **obligations stemming from the relevant international human rights treaties**: the European Convention on Human Rights and Fundamental Freedoms (ECHR), the European Convention for the Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (CPT), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of All Forms of Racial Discrimination (ICERD)<sup>21</sup> as well as to the new Convention on the Rights of People with Disabilities, which is to be ratified without undue delay by the Member States and the European Community.

### 1. Recommendations to Member States

- Review and change legislative and administrative rules to **guarantee the active involvement of users of services**, including children, in decision-making processes which concern them as well as in service design.
- **Identify legislative and administrative rules that directly or indirectly support institutionalisation or block the transition to community-based care - and change them** to support the delivery of quality services in the community.
- **Adopt strategies and action plans** based on the Common Basic Principles, accompanied by a clear timeframe and budget for the development of services in the community and the closure of long-stay residential institutions. Develop a proper **set of indicators** to measure the implementation of these action plans.
- **Use the Structural Funds for the transition from institutional to community-based care.** The European Social Fund can provide funding for the training (and re-training) of staff while the European Regional Development Fund (ERDF) can simultaneously be used for developing social infrastructure which will support the new community-based services<sup>22</sup>. Member States should ensure that funds from the ERDF are not used to build new segregating residential institutions and that their use for improving the infrastructure of existing ones, if allowed at all, is tied with investment into systemic care reform and does not exceed 10% of the overall expenses.
- **Establish systems of mandatory quality monitoring related to the quality of life of the users** rather than input indicators. These systems should be based on the involvement of users, their families and their representative organisations in the monitoring process.

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<sup>21</sup> This is particularly relevant in the context of clear over-representation of the Roma in institutional child care in several Member States.

<sup>22</sup> In early 2009, the European Commission launched a collaborative exercise with Bulgaria which aims at the use of Structural Funds (both ERDF and ESF) for the build-up of community care centres, facilitating the deinstitutionalisation process. This example could potentially be replicated in other Member States.

- **Promote improved working conditions of professional carers**, aiming to make the jobs in the sector attractive. **Require that bodies representing, training and accrediting the professional practice of staff** working with elderly people, children, persons with mental health problems 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.
- **Provide systematic support to informal carers** (above all family carers) to ensure the quality of care provided by them as to well as to preserve their own quality of life.
- **Ensure coordination of different government departments and agencies involved in the transition process.** 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.

## 2. Recommendations to the European Commission

- **Present a Communication on the transition from institutional to community-based care**, including the Common Basic Principles to be implemented in the process of transition.
- **Build the Common Basic Principles into all the relevant EU Policies** (e.g., Disability, Social Protection and Social Inclusion, Employment, Equal Opportunities, Regional Development, Health, Education, Research, Children's Rights, External Relations). In particular build them into:
  - a) the next **EU Disability Strategy** (from 2010 onwards) which will provide a coordination framework to contribute to the **implementation of the United Nations Convention on the Rights of Persons with Disabilities** at EU and Member States level, including the right of all persons with disabilities to live independently and be included in the community, and supporting voluntary commitments from the Member States and increasing cooperation between the Member States and the Commission;
  - b) the **Open Method of Coordination on Social Protection and Social Inclusion**, promoting mutual learning and enhancing the Member States' efforts towards the transition from institutional to community-based services<sup>23</sup>. Ask Member States to provide more specific information, including numbers of people in institutions and those receiving community-based or home care. Identify persons leaving institutional care among priority target groups of the Active Inclusion Strategy;
  - c) the **EU Health Strategy**, in relevant initiatives such as the ones on healthy ageing and on Alzheimer's disease and other dementias, the conclusions on the Green Paper consultation on the EU health workforce and the events to implement the European Pact for Mental Health and Well-being.
- **Provide Guidelines on the use of the Structural Funds and other EU funding instruments for deinstitutionalisation.** In these Guidelines, provide examples of good

<sup>23</sup> As highlighted in the 2009 EU Joint Report on Social Protection and Social Inclusion.

practice on how Structural Funds and other EU funding instruments can support projects on the development of community-based alternatives to institutions, by means of identifying procedures and main actors to be involved. Make clear that projects which aim to build, enlarge or perpetuate institutions are not in line with the Convention on the Rights of Persons with Disabilities and EU's own policies on equal opportunities, social inclusion and discrimination, and are therefore not eligible for funding.

- Promote and facilitate **exchange of models of good practice**, e.g., by earmarking Life-Long Learning budgets to allow service managers and service developers to learn more with regard to success stories. Facilitate the development of **training modules for first line staff and management** on how to convert from institutional care to community support. The Life-Long Learning programme (Leonardo or Grundtvig) could provide earmarked budgets.
- **Establish a pool of independent experts on deinstitutionalisation** which can provide technical assistance to the Commission itself and above all to the Member States when allocating resources from the Structural Funds. Use funding from the technical assistance budget within the Operational Programmes to establish this pool of experts (including all stakeholders).
- **Improve the knowledge base** by defining - together with EUROSTAT and in close cooperation with the Member States - a minimum data set for residential 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.
- **Fund research that will facilitate the transition from institutions to community-based services.** This can include a study on how to support users in the process of choosing their living arrangements and concluding legally valid support contracts with service providers in the implementation of Article 12 of the Convention, as well as a legal analysis of Member State legislation which directly - as well as indirectly - promotes institutionalisation.
- **Raise awareness within the European Commission** (about the right to live independently in the community and the need to develop community-based service) across the various General Directorates and across the relevant geographical units dealing with the Structural Funds, by a number of means such as trainings, workshops, publications.
- Raise the issue of investing into community-based care in the debate on the **future of Cohesion Policy after 2013.**
- **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

elderly 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 organisations representing users 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.