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STUDY ON DEINSTITUTIONALIZATION OF CHILDREN AND ADULTS WITH DISABILITIES IN EUROPE AND EURASIA

FINAL REPORT

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It was prepared by the European Network for Independent Living for JBS International.

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LIST OF ACRONYMS

CEE/CIS	Central and Eastern Europe/Commonwealth of Independent States
CEG	*Common European Guidelines on the Transition from Institutional to Community-based Care*
CRC	UN Convention on the Rights of the Child
CRPD	UN Convention on the Rights of Persons with Disabilities
DALY	Disability-Adjusted Life Year
DECLOC	*Deinstitutionalization and community living – outcomes and costs: report of a European Study*
DI	Deinstitutionalization
DRI	Disability Rights International
EC	European Commission
ECCL	European Coalition for Community Living
EU	European Union
FB&H	Federation of Bosnia and Herzegovina
HRC	UN Human Rights Committee
ICCPR	International Covenant on Civil and Political Rights
M&E	Monitoring and Evaluation
OHCHR	Office of the High Commissioner for Human Rights
PA	Personal Assistance
RS	Republika Srpska
TransMonEE	Transformative Monitoring for Enhanced Equity
YLD	Years Lost to Disability
YLL	Years of Lost Life

TABLE OF CONTENTS

EXECUTIVE SUMMARY

1. INTRODUCTION

The situation of people with disabilities living in many parts of the Europe and Eurasia (E&E) region is precarious. The prevalence of institutionalization of people with disabilities is high, and their living conditions and quality of life in many institutions are extremely poor. Despite the gradual change in attitudes towards disability over the last twenty years, despite the proliferation of policies to promote the social inclusion of people with disabilities, and despite an increased recognition of their rights—most recently, in the UN Convention on the Rights of Persons with Disabilities (CRPD)—the lack of community-based support means that even people with disabilities who remain with their families are often isolated in their own homes.

Although there is a wide consensus on the need for action to ensure the transition from institutional care to community-based services, this has yet to be translated into practice. Institutionalization remains the predominant form of care for people with disabilities and progress in developing community-based alternatives has been disappointingly slow. The key finding of this study is that without a clear focus on taking action to develop community-based services as alternatives to institutional care, people with disabilities will continue to be institutionalized.

1.1 PURPOSE AND SCOPE OF THIS REPORT

This report sets out the findings of a study undertaken on behalf of the United States Agency for International Development (USAID). It considers why there has been so little progress by governments in developing community-based alternatives to institutional care of children and adults with disabilities in the E&E region. The report then suggests the concrete actions needed to provide services and support that enable people with disabilities to experience *community living*—to live and participate in community life as equal citizens. The report provides:

- An overview of the current situation of people with disabilities in Europe and Eurasia, focusing on the countries in which USAID has Missions or interest—Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Georgia, Kosovo, the Republic of Macedonia, Moldova, Montenegro, the Russian Federation, Serbia, and Ukraine—referred to collectively in this report as "the E&E region." (Chapter 2)

- Information on key principles and elements of *deinstitutionalization*—the process of working toward the closure of long-stay institutions by developing alternative community-based services and supports for people with disabilities. (Chapter 3)

- Progress made and challenges encountered in the deinstitutionalization process. (Chapter 4)

- Recommendations for USAID Missions interested in deinstitutionalization programs. (Chapter 5)

- Detailed background information, references, and program planning resources. (Annexes)

1.2 STUDY METHODOLOGY

This study is based on desktop research conducted by the authors using a wide range of resources, including information from interviews with representatives of nongovernmental organizations (NGOs) working in the region. The authors were limited by a chronic shortage of comprehensive, accurate, and disaggregated data across the region, particularly related to adults with disabilities.

2. CURRENT STATUS OF PEOPLE WITH DISABILITIES IN THE REGION

While it is difficult to obtain accurate figures, the available information demonstrates that large numbers of people with disabilities are placed in long-stay institutions. Current estimates suggest that over 600,000 adults and children with disabilities live in institutions across the region that is the focus of this study—the 13 countries identified above. Uncertainty about the actual numbers is mainly due to the lack of comprehensive data collection by governments, but differences in definitions, and the uncertain accuracy of existing data, are complicating factors.

In spite of the lack of data about the number of people in institutional care, confinement in institutions is now widely recognized as inherently a human rights violation. Residents are segregated from society, often in closed facilities and often for life. Under these circumstances, they are often subject to serious *abuses* and *infringements* of their human rights. Long-term institutionalization physically, mentally, and emotionally damages all people, but especially children. Residents in institutions have little or no contact with the outside world. They have no opportunity to participate in every-day life activities such as going to school, getting a job, or going out with friends.

Institutionalization contravenes Article 19 of the CRPD (living independently and being included in the community) that provides for the "equal right of all persons with disabilities to live in the community with choices equal to others." Deinstitutionalization—the development of community-based support services and closure of institutions—is necessary to ensure the inclusion, independence, and participation of people with disabilities in society.

3. DEVELOPING ALTERNATIVES TO INSTITUTIONAL CARE

3.1 TEN ELEMENTS OF DEINSTITUTIONALIZATION

To implement the transition from a system of long-stay residential institutions to a system of community-based services—deinstitutionalization— successfully requires that governments create sustainable strategies and action plans. This transition is a complex, long-term process. It requires careful planning with a wide range of cooperating organizations and individuals to ensure a coordinated approach. *The Common European Guidelines on the Transition from Institutional to Community-based Care*, published in November 2012—commonly referred to as the "Common European Guidelines" (CEG)—draws together current European and international best practices to "provide practical advice about how to make a sustained transition from institutional care to family-based and community-based alternatives" (European Expert Group, 2012, p. 15).

The Common European Guidelines' practical advice for sustained transition

1. Make the case for developing community-based alternatives to institutions
2. Assess the situation
3. Develop a strategy and an action plan
4. Establish the legal framework for community-based services
5. Develop a range of services in the community
6. Allocate financial, material and human resources
7. Develop individual plans
8. Support individuals and communities during transition
9. Define, monitor and evaluate the quality of services
10. Develop the workforce

3.2 FRAMEWORK FOR ANALYSIS

This report adapts the framework for assessing policies and practices used in USAID-funded studies (USAID 2005, USAID 2008, USAID 2010) by incorporating the ten elements of the Common European

Guidelines under master categories referred to as "pillars." The addition of a fifth category—Increasing Awareness and Participation—highlights the importance of element 8 of the Common European Guidelines (Supporting individuals and communities during transition) to successful deinstitutionalization.

The Five-Pillar Framework for Analysis

Pillar 1 — *Legal and Policy Framework* comprises elements 1, 2, 3, and 4 of the Common European Guidelines.

Pillar 2 — *Structure and Types of Programs and Services* comprises elements 5, 6, and 7 of the Common European Guidelines.

Pillar 3 — *Developing Human Capacity* corresponds to element 10 of the Common European Guidelines.

Pillar 4 — *Performance Outcomes and Measures* corresponds to element 9 of the Common European Guidelines.

Pillar 5 — *Increasing Awareness and Participation* corresponds to element 8 of the Common European Guidelines and highlights specific details related to implementing Article 4 of the CRPD.

4. PROGRESS AND CHALLENGES IN THE TRANSITION TO COMMUNITY LIVING

Using the five-pillar framework for analysis, the report describes the progress made and the challenges that remain in the shift from institutional care to community-based services and support in the region.

4.1 LEGAL AND POLICY FRAMEWORK (PILLAR 1)

Making the case for developing community-based alternatives to institutions. Governments in the region have given deinstitutionalization little attention. There are several reasons for the failure to pursue actively the process of transition: (a) the complexity of the process, (b) the perception that community-based services are too expensive, and (c) societal prejudice and discrimination against people with disabilities. Respondents to the study identified additional problems: (a) failure to recognize the need and lack of political will for reform, (b) lack of coordination between government departments, and (c) inadequate government accountability.

Assessing the current situation of people with disabilities. There are many reasons for the continued prevalence of institutionalization throughout the region: insufficient resources allocated for community-based alternatives, lack of access to mainstream services, and lack of information on the situation of people with disabilities.

Developing a strategy and action plan. In the majority of the countries in the region, there is no comprehensive strategy for planning and implementing a deinstitutionalization process for all people with disabilities (children, adults and people with mental health problems). Because achieving inclusion is a long-term challenge, without a clear focus on taking action, it is likely that institutions will remain and people with disabilities will be institutionalized.

Establishing the legal framework for community-based services. There are examples of positive reform, such as the adoption of legislation and policy measures that seek to facilitate community living and the social inclusion of people with disabilities, and reviews of legislation to ensure compliance with the CRPD. But many barriers to community living remain: gaps in laws and policies related to equal opportunities and integration of people with disabilities; inadequate mechanisms for participating in implementation of strategies and action plans; laws and policies that impede the development of community-based services; and guardianship laws that constrain the ability of people with disabilities to engage in community life.

4.2 STRUCTURE AND TYPES OF PROGRAMS AND SERVICES (PILLAR 2)

Developing a range of services in the community. Developing a range of services in the community is a vital element of the process of transition from institutional care to community living. Although some community-based services have been developed, they remain the exception.

Allocating financial, material and human resources. An inadequate understanding of the necessary legal and financial framework for community living, and continued allocation of resources to institutional care rather than community-based alternatives, remain barriers to reform.

4.3 DEVELOPING HUMAN CAPACITY (PILLAR 3)

Developing the workforce. The lack of a well-trained professional workforce is one of the key obstacles to providing quality community-based services. Low salaries, high staff turnover, and the lack of appropriate professional training create major barriers to social inclusion and community living.

4.4 PERFORMANCE OUTCOMES AND MEASURES (PILLAR 4)

Defining, monitoring and evaluating the quality of services. Despite the importance of defining and implementing quality standards, and monitoring and evaluating services, this key area has received little attention to date. Lack of information makes it difficult to ascertain whether governments have made progress in developing performance outcomes and measures.

4.5 INCREASING AWARENESS AND PARTICIPATION (PILLAR 5)

Supporting individuals and communities during transition. Negative attitudes toward people with disabilities and the lack of capacity of people with disabilities and parents of children with disabilities to advocate for necessary reform remain significant barriers to community living.

5. CONCLUSIONS AND RECOMMENDATIONS

The following recommendations suggest effective ways for USAID Mission staff to support governments' strategic planning and deinstitutionalization activities by: (a) addressing existing and potential barriers that impede the transition to community living, and (b) seizing current opportunities to advocate for necessary changes. Given the complexity of the deinstitutionalization process and the lack of information to guide reform, this support necessarily begins with facilitating official action and in-depth analysis of the situation in each country.

RECOMMENDATION 1. Make the case for developing community-based alternatives to institutions (CEG1)

1. USAID Missions need to highlight the need for reform and persuade governments that urgent action is required to develop community-based services.

2. Fund projects and provide technical assistance for the development of a more effective means of collecting data on disability, taking into account Article 31 of the CRPD, which requires States to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the [CRPD]."

3. Make clear to potential grantees that services that reinforce social exclusion and segregation of people with disabilities, contrary to Article 19 of the CRPD, will not be supported. All available funding should go toward developing quality community-based alternatives to institutionalization and should accord with any existing deinstitutionalization strategy.

RECOMMENDATION 2. Assess the situation in each country (CEG2)

USAID Missions that wish to initiate new or develop existing deinstitutionalization projects should support an in-depth analysis of the countries in which they are working. A comprehensive, in-depth assessment of the situation in a country should cover: (a) the needs of children and adults with disabilities and how social care, health care, and educational systems respond to them; (b) the barriers to using mainstream services; (c) the situation of people with disabilities and the reasons for institutionalization; (d) an assessment of the resources currently available within the child protection, social care, health, and education systems, and information about existing community-based services.

1. Highlight the need for an in-depth, country-by-country analysis and where appropriate provide financial and technical assistance for such studies.
2. Provide funding for a range of activities, such as workshops and seminars on how to develop a vision for community living, to engage all individuals and organizations that have responsibility for or an interest in providing services for people with disabilities. The purpose of such activities is to help develop among all stakeholders, including relevant Ministries, such as those responsible for finance, a common understanding of what needs to be accomplished and a recognition of the importance of coordinated efforts to complete the agreed actions within agreed timescales.

RECOMMENDATION 3. Develop strategies and action plans (CEG3)

1. Help governments draft and implement deinstitutionalization strategies and action plans by providing technical assistance to their task forces and working groups. Involve all relevant government departments and organizations representing the interests of people with disabilities.
2. Fund capacity building activities that will enable local authorities to assess the needs in their local communities and assist local authorities in developing strategies and action plans.
3. Coordinate deinstitutionalization projects with other international donors that share an interest in disabilities, social and health care reform, and link these projects with a country's existing deinstitutionalization strategy and action plan or strategy development work.
4. Support study visits, training, and other activities that build local and regional actors' capacity to (a) implement deinstitutionalization programs and (b) support people with disabilities to live in the community.

RECOMMENDATION 4. Establish the legal framework for community-based services (CEG4)

1. Support government reviews of legislation and policy, including legal capacity legislation, in accordance with the CRPD. The review process should include: (a) detailed analysis and recommendations on law and policy, including a timeframe for implementation and a monitoring mechanism, and (b) review of administrative rules on providing and financing services to establish whether they create obstacles to deinstitutionalization.
2. Fund training on the CRPD and the Convention on the Rights of the Child (CRC) for all relevant stakeholders, including government departments and agencies, social and health care professionals, other service providers, trade unions, people with disabilities and their families. Include organizations representing people with disabilities in preparation and delivery.

RECOMMENDATION 5. Develop a range of services in the community (CEG5)

1. Fund support for implementing pilot projects of innovative services such as early intervention and other preventive services, foster care, family support services, personal assistance, supported living, supported employment, inclusive education, and personal budgets. These innovative services should be cost effective, based on European and international good practice, and should be part of an overall deinstitutionalization strategy. In developing such services, consideration should be given to sustainability of funding and to how they relate to the five pillars.
2. Support ongoing reforms by organizing study visits and exchanges for policy makers, service providers, professionals, and organizations of people with disabilities to countries demonstrating good deinstitutionalization practices and trainings involving European and international experts. In countries where nongovernmental organizations are providing community-based services and

advocating for community living, funding could be made available to organizations willing to develop training programs and study visits on a national and international basis. This will address the issue of lack of knowledge on how to develop community-based services.

3. Fund deinstitutionalization initiatives that make mainstream services available and accessible to people with disabilities. Ensure that people with higher support needs are served from the beginning so that experience and know-how can immediately benefit people with lower support needs. International funding should be used to support parts of the deinstitutionalization process that cannot be covered by the government, such as development of mainstream social housing to support new services in the community.

RECOMMENDATION 6. Allocate financial, material, and human resources (CEG6)

1. Fund national studies comparing the cost of institutional care with community-based services to ensure that government planning for the transition to community-based services anticipates the initial investments (hump costs) and transition funding needed while two systems run in parallel.

2. Provide technical assistance to help governments develop targeted funding strategies for all stages of deinstitutionalization and development of community-based services.

RECOMMENDATION 7. Develop individual plans (CEG7)

Provide technical assistance to help governments develop effective case management and gatekeeping mechanisms to ensure that people receive services appropriate to their needs.

RECOMMENDATION 8. Develop the workforce for deinstitutionalization (CEG10)

Fund the development of training modules and delivery of initial and ongoing training of staff to work in community-based services. Training should focus on showing that the move towards community-based services must be accompanied by a shift towards a social model of disability, which helps professionals see that the main disabling factors are physical and attitudinal barriers in the environment that can and must be removed so individuals can fully participate in society.

RECOMMENDATION 9. Define, monitor, and evaluate the quality of services (CEG9)

1. Support capacity building to help policy makers at the ministerial level develop effective mechanisms to ensure meaningful participation of civil society actors (non-governmental organizations with experience delivering community-based services, organizations of people with disabilities, individuals with disabilities and their families) in developing monitoring and evaluation standards, and in implementing, monitoring and evaluating services.

2. Fund assessment and demonstrate positive outcomes for persons with disabilities involved the pilot projects suggested in Recommendation 5-1 and 5-2 above.

RECOMMENDATION 10. Support individuals and communities during transition (CEG8)

1. Provide technical and financial support so that organizations representing people with disabilities or advocating for community living can take part in drafting and implementing deinstitutionalization strategies and action plans, and in monitoring and evaluation activities.

2. Provide funding to enhance capacity building (e.g., training in advocacy and policy development) so that organizations representing children and people with disabilities can participate meaningfully in reviews of policy, legislation, and other matters concerning the deinstitutionalization process.

3. Support public awareness campaigns on the right of people with disabilities to live in the community.

1. INTRODUCTION

The situation of people with disabilities living in many parts of the Europe and Eurasia (E&E) region[1] is precarious. The prevalence of institutionalization of people with disabilities is high, and their living conditions and quality of life in many institutions are extremely poor. Those who remain with their families, "may fare little better because their relatives are likely to have little to no support in caring for them" (Open Society Foundations, 2011, p. 4). Such concerns were articulated by Thomas Hammarberg, former Council of Europe Commissioner for Human Rights in 2012:

> *For most people, being a part of a particular society's fabric is taken for granted and we might not even think about it. This is not the case when people with disabilities are concerned. Whether due to stigma, inaccessibility of places, technologies, services and social structures, or lack of support within the community, people with disabilities have been isolated and segregated from their communities. People in many countries are confined to institutions, and therefore segregated from the community. In institutions, they are at risk of exploitation, violence and abuse. Countless more people with disabilities are physically located in their communities, but are barred from meaningful participation in the life of their communities because either services are not available or communities are organized in ways that exclude them from participation. (Council of Europe Commissioner for Human Rights, 2012b, p. 8)*

Over the last twenty years, there has been a gradual change in attitudes towards disability as well as a proliferation of policies to promote the social inclusion of people with disabilities and an increased recognition of their rights. The UN Convention on the Rights of Persons with Disabilities (CRPD) is a prime example of changing attitudes. There is also widespread consensus that segregating people with disabilities in long-stay institutions is not an acceptable practice in the 21st century. The Council of Europe's 2006-2015 disability action plan, for example, calls on all member states to promote the rights of people with disabilities and recommends specific actions that will ensure a shift from the institutional care system to "the provision of community-based quality support services to enable people to live in their communities and enhance their quality of life" (Council of Europe Committee of Ministers, 2006). These recommendations are crucial because the lack of support services is often the primary reason why a child or adult with disabilities is institutionalized in the first place.

Current practice, however, does not often reflect changing attitudes and beliefs. Progress in developing community-based alternatives to institutionalization has been disappointingly slow. *A Strategic Approach to Characterizing the Status and Progress of Child Welfare Reform in CEE/CIS Countries* came to the following conclusions in relation to children at risk of being institutionalized, including those with disabilities:

> *Since the dissolution of the Soviet Union, some of the countries in the CEE/CIS region have begun to reform their child welfare systems and to provide family-care alternatives to institutionalization (e.g., non-relative foster care, guardianship/kinship care, adoption), as well as community-based social services aimed at helping at-risk parents keep their children rather than relinquishing them to state care. Progress in this regard has been very uneven from country to country, and different social, cultural, and political factors influence the nature and extent to which countries are moving to deinstitutionalize their child welfare systems. (University of Pittsburgh Office of Child Development, Creative Associates International & Aguirre Division of JBS International, Inc., 2008, p. 1)*

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[1] This report focuses on current and former USAID-presence countries of Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Georgia, Kosovo, the Republic of Macedonia, Moldova, Montenegro, Russia, Serbia, and Ukraine. At times, there are references to Council of Europe and UN regions, which include E&E countries (see Annex 1 for country lists).

1.1 SCOPE AND PURPOSE OF THIS REPORT

This report considers the development of community-based alternatives to the institutionalization of children and adults with disabilities in the E&E region. The study has four aims:

- Provide an overview of the current situation of people with disabilities in the E&E region.
- Highlight best practice guidance on developing alternative community-based services and supports for people with disabilities and preventing institutionalization — the process often referred to as "deinstitutionalization."
- Analyze why governments have made so little progress in replacing institutional care with services and support that enable people with disabilities to live and participate in community life as equal citizens, and identify gaps and challenges that need to be addressed in order to improve the situation.
- Recommend concrete actions USAID Missions in the region might take to: (a) focus on people with disabilities in Missions' existing child welfare or deinstitutionalization programs, and (b) design new programs that provide community-based services to children or adults with disabilities.

1.2 STUDY METHODOLOGY

This study is based on desktop research conducted by the authors using a wide range of resources, including information from interviews with representatives of nongovernmental organizations (NGOs) working in the region. These representatives were chosen for their direct work experience with the deinstitutionalization process in their countries. They were asked questions about the current situation of children and adults with disabilities, legal and policy frameworks that support deinstitutionalization, and the transition from institutional care to community-based support in their countries. In addition, interviewees were asked to provide information on statistics that could be accessed by the authors. Generally, the authors collected available statistical data from reports by donors, NGOs, and governments, as well as through searches of government, NGO, and intergovernmental organization websites. Annex 2 contains the questions used in the study and Annex 3 contains a list of the persons who provided information for this study.

Study Limitations. There is a chronic shortage of comprehensive, accurate, and disaggregated data across the region, particularly related to adults with disabilities. Given the time restraints of this study, it was difficult to obtain up-to-date information on Ukraine and Montenegro.

1.3 UNDERSTANDING KEY TERMS

A potential source of confusion when discussing deinstitutionalization is the meaning of "institution" and how this term compares to residential care, formal care, and alternative care. It is also helpful to clarify what community-based services and community living mean in this context. These terms are defined below.

Institution. This report adopts the approach taken by the *Common European Guidelines on the Transition from Institutional to Community-based Care* (European Expert Group, 2012, p. 25), which avoids defining an institution by the number of people living in the premises and focuses instead on the residents' experience of a specific institutional culture. Thus, an institution is any residential care where:

- Residents are isolated from the broader community and/or compelled to live together.
- Residents have insufficient control over their lives and the decisions that affect them.
- The requirements of the organization tend to take precedence over the residents' individualized needs.

Institutionalization. While the factors listed above are usually present in the traditional large, long-stay institutions that continue to exist in the region, the World Health Organization (WHO)'s use of the term "institutionalization" emphasizes that the problem lies as much in the manner in which services are delivered as the size of the building:

> *Institutionalization as a problem is not restricted to large long-stay institutions. Children with intellectual disabilities living in smaller-scale settings, including with their biological families, in foster homes or other family-like residential placements, can also be denied social, educational and economic opportunities. Kept at home, educated separately and insulated from or rejected by their communities, these children can be just as isolated "in the community" as in large-scale institutions. The proposal has…been made to broaden the definition of institutionalization to refer to the overall phenomenon in which an individual with a disability loses control over his or her own life. (WHO, 2010, p. 10)*

Deinstitutionalization. The process of managing the transition from institutional care to community living.

Residential care. Care provided outside the individual's home that can include both traditional long-stay institutions and residential care settings within the range of community-based services provided to meet the needs of people with disabilities.

Formal care. "All care provided in a family environment which has been ordered by a competent administrative body or judicial authority, and all care provided in a residential environment, including in private facilities, whether or not as a result of administrative or judicial measures" (UN GA, 2010, p. 6).

Alternative care. "Care provided to children deprived of parental care. It does not refer to alternatives to institutional care, since alternative care can include institutions for children" (European Expert Group, 2012, p. 28).

Community-based services. "Not only special services for people with disabilities (such as early intervention, personal assistance, rehabilitation, family support services…), but also services for the general population (such as housing, education, health care, transport…) which must be made responsive to the needs of people with disabilities" (European Coalition for Community Living, 2010, p. 77).

Community living. This term—sometimes referred to as independent living—describes the goal that "People with disabilities…live in their local communities as equal citizens, with the support…to participate in every-day life.…living in their own homes or with their families, going to work, going to school and taking part in community activities" (European Coalition for Community Living, 2008, p. 71).

1.4 GUIDELINES FOR THE TRANSITION TO COMMUNITY-BASED CARE

The *Common European Guidelines on the Transition from Institutional to Community Based Care* were published in November 2012 after consultation with European networks representing children, people with disabilities, mental health organizations, families, and older people; public and nonprofit service providers; policy-makers; and experts in all aspects of the transition from institutional to community-based care. The guidelines are a compilation of current European and international best practices and have been endorsed by the European Commission (EC) as a standard towards which countries in the European Union (EU) should strive. They "provide practical advice about how to make a sustained transition…to family-based and community-based alternatives for individuals currently living in institutions and those living in the community, often without adequate support," and can therefore be used by governments in the E&E region to plan and implement deinstitutionalization initiatives.

Deinstitutionalization requires careful planning in cooperation with a wide range of organizations and individuals to ensure a sustainable, coordinated approach with well-defined goals, effective strategies, and practical action plans, timescales and the means to measure progress. The ten elements of the process are:

1. Making the case for developing community-based alternatives to institutions
2. Assessing the situation
3. Developing a strategy and an action plan
4. Establishing the legal framework for community-based services
5. Developing a range of services in the community
6. Allocating financial, material, and human resources
7. Developing individual plans
8. Supporting individuals and communities during transition
9. Defining, monitoring, and evaluating the quality of services
10. Developing the workforce

These ten elements describe a range of actions governments need to take in order to implement successfully the transition from institutional care to a system of community-based services for persons with disabilities, persons with mental health problems, and older persons in Europe. They are referred to frequently in the report and discussed in more detail in Chapter 3.

1.5 FRAMEWORK FOR ANALYSIS OF THE TRANSITION TO COMMUNITY-BASED CARE

This report incorporates the key elements from the Common European Guidelines into a five-pillar framework for assessing policies and practices. Previous studies funded by the USAID E&E Bureau's Social Transition Team have relied on four pillars for assessing policies and practices (e.g., Davis, 2005). However, this report suggests it is necessary to add a fifth pillar on Increasing Awareness and Participation, which will be relevant to all the activities undertaken within the first four pillars.

TABLE 1.

Framework for Analysis — Transition from Institutional Care to Community Living according to the Common European Guidelines

Pillar Number	Reform Element	Key Actions
Pillar 1	**Legal and Policy Framework**	Making the case for developing community-based alternatives to institutions Assessment of the situation Developing a strategy and an action plan Establishing the legal framework for community-based services

Pillar 2	**Structure and Types of Programs and Services**	Developing a range of services in the community Allocating financial, material and human resources Developing individual plans
Pillar 3	**Developing Human Capacity**	Developing the workforce
Pillar 4	**Performance Outcomes and Measures**	Developing, evaluating and monitoring the quality of services
Pillar 5	**Increasing Awareness and Participation**	Supporting individuals and communities during transition

This framework specifies the key areas that need to be considered for a comprehensive understanding of the current situation of children and adults with disabilities living in the region and the extent of the transition from institutional care to community-based services and support. It thus can be used to plan and implement deinstitutionalization initiatives and support governments in the region that are engaged in this transition process. The pillars may be described as follows:

Pillar 1—Legal and Policy Framework. The policies and laws that reflect European and international human rights standards and internationally recognized best practices for developing community-based alternatives to institutional care for children and adults with disabilities, including the legal and financial mechanisms to support planning and delivery of these services.

Pillar 2—Structure and Types of Programs and Services. The key issues to be addressed when developing comprehensive, community-based care and support services that enable people with disabilities to live and participate in the community on an equal basis with other citizens.

Pillar 3—Developing Human Capacity. The professional education and training, curriculum development, professional regulation (registration and standards of practice), and performance monitoring for people involved in the deinstitutionalization process, particularly the front-line workers, supervisors, managers, and administrators responsible for planning and providing community-based services for people with disabilities.

Pillar 4—Performance Outcomes and Measures. How outcomes are defined, measured, and monitored in government policies, strategies, and donor interventions (e.g., reduced dependency on institutionalization or increased utilization of community-based care).

Pillar 5—Increasing Awareness and Participation. How people with disabilities and other stakeholders are consulted and actively involved in developing and implementing legislation and policies, and in other decision-making processes that affect them.[2] Participation includes individuals and organizations with an interest in deinstitutionalization and the rights of people with disabilities.

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[2] Article 4(2) of the CRPD states: "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."

2. CURRENT STATUS OF PEOPLE WITH DISABILITIES IN THE E&E REGION

Although increasingly recognized as an unacceptable practice in the 21st century, institutionalization remains the predominant form of "care" in the E&E region. This Chapter presents what is known about the prevalence of disability and institutionalization and assesses the current situation of children and adults with disabilities in the E&E region. It describes the causes and negative impact of institutionalization, identifies the human rights violations that contravene the right to community living, and discusses how community-based services are a better use of resources than institutional care.[3]

The UN Convention on the Rights of Persons with Disabilities (CRPD), which came into force in 2008 (UN Enable, n.d.), is the first human rights treaty to make the right to community living explicit. The box below highlights the importance of Article 19 of the CRPD.

2.1 PREVALENCE OF DISABILITY

THE RIGHT TO COMMUNITY LIVING: ARTICLE 19 OF THE CRPD

Many European and international human rights standards, recommendations, and policies now highlight states' responsibilities to: (1) respect and promote the rights of people with disabilities and, (2) take action to ensure their inclusion and participation in society (European Expert Group, 2012, p. 34–43).

Article 19 of the CRPD requires states that are party to this treaty to "recognize the right of people with disabilities to live in the community, with choices equal to others" and to "take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community." States must ensure that people with disabilities have access to community services "necessary to support living and inclusion in the community" and to "prevent isolation and segregation from the community."

Although Article 19 does not include a specific requirement to close institutions and replace them with community-based services, advocates argue that such actions are implicitly required because they are an essential step if the right to community living is to be met:

> *The Article 19 requirement that States Parties ensure that persons with disabilities have access to community services that support their social inclusion and "prevent isolation or segregation from the community" cannot be achieved if people with disabilities continue to be placed in institutions, preventing them from developing and maintaining relationships with their family, friends, and the wider community (OSF, 2012, p. 71).*

Source: UN Enable, n.d.

Table 2 shows the World Health Organization 2011 estimates of the prevalence of disability as years lost to disability (YLD)[4] for all countries in the region except Kosovo. Based on this measure, the three countries with the highest prevalence of disability were Moldova, Russia, and Ukraine (WHO, 2011, p. 271–276).

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3. Available detailed data on the prevalence of institutionalization in the region are presented in Annex 4, which also provides further information on concerns about data collection and available information on children and adults with disabilities living in residential care in the region.

4. Years of Life Lost (YLL) and Years Lost due to Disability (YLD) are the two components of the Disability-Adjusted Life Year (DALY)—the World Health Organization's measure of the "burden of disease" and disability on societies. One DALY can be thought of as one lost year of "healthy" life, calculated as the sum of Years of Life Lost (YLL) due to premature mortality in a population and Years Lost due to Disability (YLD) *for incident cases of the health condition*. For further information on this calculation of the prevalence of disability, see http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/

TABLE 2.

Prevalence of Disability in Europe and Eurasia (years lost to disability [YLD] per 100 persons)

Country	Yrs/100 persons
Albania	7.8
Armenia	7.9
Azerbaijan	8.2
Belarus	8.4
Bosnia and Herzegovina	7.6
Georgia	7.6
Kosovo	—

Country	Yrs/100 persons
Republic of Macedonia	7.3
Moldova	8.6
Montenegro	7.4 (N=69)
Russian Federation	10.0
Serbia	7.4 (N=93)
Ukraine	8.8

Source: World Health Organization and World Bank. 2011. *World Report on Disability 2011.*

2.2 PREVALENCE OF INSTITUTIONALIZATION

Reliable data on the numbers of people with disabilities living in institutions in Europe and Eurasia is difficult to obtain.[5] While this difficulty is mainly due to the lack of comprehensive data collection by governments, other factors are also relevant, such as differences in definitions (for example, *disability* and *institution*) and the accuracy of the data collected. Generally, there is more information available about children in institutions, including children with disabilities, than for adults with disabilities.

> *Information about the number of adults with disabilities in the E&E region is more elusive than that for children with disabilities. Statistics on the overall numbers of disabled pensioners and recipients of the disability social-welfare system are published according to the individual's status within the benefit structure. Comparable statistical information on institutionalized adults in the region is not available. (USAID, 2009c, p. 17)*

The institutionalization of infants and children in the region. UNICEF (2011), in collaboration with the Office of the High Commissioner for Human Rights Regional Office for Europe, launched a "Call for Action" in 2011 to end the placement of children under three years of age in institutions. UNICEF (2010) declared that across the 22 countries in CEE/CIS[6], which includes the E&E region, more than 626,000 children resided in institutional care (p. 4). While the rate of children in institutional care "has on average been almost stagnant since 2000," in some countries, the rate of institutional care increased between 2000 and 2007, indicating that "despite ongoing reforms, institutional care is becoming more frequent in more than half the countries" (p. 20). Also, in 16 countries of the E&E region for which data were available, information "suggests that there are well over 28,000 children below three years of age placed in institutional care" (UNICEF, 2011).

UNICEF's Transformative Monitoring for Enhanced Equity (TransMonEE) Database provides information on all E&E countries with the exception of Kosovo. TransMonEE residential care figures include children in infant homes, orphanages, boarding homes and schools for children without parental care or poor children, boarding homes and schools for children with disabilities, family-type homes, and SOS villages.[7] The latest available information is for children in residential care during 2010. Among the 438,000

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[5] The available estimates and explanations of how these were reached are presented in Annex 4.

[6] The CEE/CIS region includes Bulgaria, Romania, Albania, Bosnia and Herzegovina, Croatia, Montenegro, Serbia, the Republic of Macedonia, Belarus, Moldova, Russia, Ukraine, Armenia, Azerbaijan, Georgia, Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan.

[7] SOS villages are run by SOS Children's Villages International (an NGO). The service consists of family-type homes for groups of children, headed by an SOS mother/parent. A number of such homes are grouped together to form a "village". Source: SOS Children's Villages International.

children living in residential care, 165,895 were children with disabilities, although the data did not indicate how many of these children were in institutional care.[8]

2.3 FACTORS LEADING TO THE INSTITUTIONALIZATION OF PEOPLE WITH DISABILITIES, HIGHLIGHTING CHILDREN AND YOUTH

The Open Society Foundation (OSF) (2011) cited the severe shortage of community-based services that would enable people to live in their own homes and participate in community life as the primary reason for the continued institutionalization of people with disabilities. This is confirmed by the findings of this study, which also identifies related factors that contribute to the institutionalization of children and adults with disabilities.

Inability to access specialized or mainstream *services*. The lack of specialized services for children and adults with disabilities, as well as inaccessibility of mainstream services such as education, health care, transport and childcare contributes to institutionalization.

> "In short, main factors are lack of services both for young children and adults whose families cannot take care of them any longer and the attitude of 'professionals,' especially medical doctors and 'defectologists' advising families to give up their child and put it in an institution" (Serbia, personal communication, 2012).

UNICEF (2010) indicated that "overall the data available support the view that in CEE/CIS the majority of children with disabilities lack the care and support necessary for them to lead an active life as a member of their community" (p. 29). Respondents from several countries and recent studies confirm this assessment. For example, the failure of local governments to provide a full package of services for people with disabilities was highlighted in relation to Albania (personal communication, 2012). In Armenia, children with disabilities are in danger of being institutionalized at an early age due to the lack of community-based alternatives and psychosocial support for families, compounded by discriminatory attitudes (personal communication, 2012). UNICEF Azerbaijan (2012, p.16) found that both the lack of specialized services and the child's demand for parents' time equally contribute to child institutionalization. The absence of formal support—medical, social, and psychological services—that directly correspond to the needs of families of children with disabilities may lead parents in the Russian Federation to place their child in an institution (Rogers, 2010). Rogers (2010) also found that many children with disabilities in Russia entered institutional care between the ages of four and seven due to lack of inclusive kindergartens and schools, and in general, an inaccessible environment. Respondents to this report also noted this issue (personal communication, 2012).

***Inability of families to provide support*.** Several studies have explored why families place children in institutional care. *Lack of support from the community and family for caring for a child with a disability, leaving parents unable to cope, has been identified as one of the reasons*. UNICEF (2010) reported that more than a third of all children in residential care were classified as having a disability in CEE/CIS countries and children with actual or perceived disabilities faced a greater risk than others of being institutionalized. *The Case for Change* reported that living with and caring for a child with intellectual disabilities "can have clearly adverse effects on the health and well-being of parents, siblings and extended family members.…having a disabled child may increase stress, take a toll on mental and physical health and affect all aspects of family life" (WHO, 2010, p. 9). UNICEF (2010) suggested that one reason why parents "hand over" a child with disabilities is because they think that they are incapable of providing adequate care. "This may be due to social values and individual beliefs, lack of knowledge and training or because they lack material and economic support, including respite care and tailored services to support families in looking after children with special needs at home" (p. 29). Parents have been made to feel

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[8] Kosovo was not included, and no information on Georgia was given for 2009 and 2010. Also, no information was provided for Albania in 2010, and data collected in 2009 were used to calculate these figures.

inadequate and "can even be actively encouraged by the authorities" to hand over a child (p. 29). Some additional factors are outlined below.

Complexity of caring for a child with disabilities. Young adults in Serbia have been admitted to institutions when their parents are no longer able to look after them (personal communication, 2012). People in Need (2012, p. 158) also reported similar findings for Serbia as well as Bosnia and Herzegovina, and Kosovo. Their findings indicate that the leading reasons for institutionalizing adults are (a) absence of close relatives, (b) a family that is not prepared to look after the person, (c) socio-economic vulnerability, and (d) inadequate family care. Rogers (2010) cited the absence of informal support from relatives, friends, and other close persons as one of the reasons for institutionalizing children with disabilities in Russia.

Poverty. Family poverty is often presented as a key factor in a family's decision to place a child in formal care. Mulheir (2012) cited the additional care needs of a child with a disability that often limit parents' ability to undertake paid employment and highlights the link between poverty and disability: "disability causes poverty and poverty causes disability" (p. 126). This connection was confirmed by an interviewee in Azerbaijan (personal communication, 2012), as well as UNICEF. The report *Study for Mid-term Review of the State Program on Deinstitutionalization and Alternative Care in Azerbaijan* (UNICEF, 2012) found that many parents lack basic parenting skills and when economic conditions are harsh, some families cannot allocate enough time and care for a child with a disability and opt for institutionalization. Moreover, UNICEF noted that often families, in particular parents of children with disabilities "are simply seeking day-care services or educational facilities in their localities, and when they are unavailable, they decide to send their children to boarding schools or other institutions" (UNICEF, 2010, p. 17). For single parents in particular, the inability to take care of their children while working can be a determining factor for placement in an institution (p. 16).

Migration of parents. Innocenti Research Center findings suggested that in some countries children are placed in institutions because their parents left the country to seek work. Moldova and Albania are two extreme examples. In 2005, an estimated 700,000 people (17 percent of the population of Moldova) and an estimated 860,000 people (28 percent of the population of Albania) were living abroad (UNICEF, 2009, p. 94).

Active recruitment of children by institutions. In Azerbaijan, it has been reported that during the summer, institutional staff members persuade very poor families to give their child to state care, whether or not the child has a disability. The "active recruitment of children by teachers/carers of institutions" has been driven by their need to fill all available beds because their funding is based on *bed occupancy* (personal communication, 2012).

Lack of basic knowledge of human rights coupled with stigma and discrimination. UNICEF (2010) found that "High rates of institutionalization indicated high levels of stigma and discrimination by professionals and public" (p. 29). Several sources confirmed this finding in relation to both children and adults with disabilities. In Azerbaijan, it was reported that pressure and shame may lead to a parents' decision to place a child or family member in institutional care (personal communication, 2012). In Serbia, parents are often advised by doctors to leave their disabled child in an institution, where s/he will allegedly get better care, and to focus on their "normal" children (personal communication, 2012). Mulheir (2012) reported that people with disabilities from ethnic minorities have been doubly disadvantaged in dealings with social and welfare institutions and in their vulnerability to racially motivated abuse and discrimination (p. 128). In Moldova, parents of people with disabilities are reported to have little awareness of their right to live in the community (personal communication, 2012). Similarly, in Georgia, there have been few examples demonstrating that people with disabilities can live in the community (personal communication, 2012).

Inadequate funding and limited access to services. In Moldova, non-availability of personal budgets, limited financial resources, and a low level of competence have prevented local authorities from responding to the complex needs and supporting the social inclusion of people with disabilities (personal communication, 2012). Low disability pensions and not being able to "survive" in the community and access the necessary services have been cited as reasons for institutionalization (personal communication, 2012). In Belarus, people with physical disabilities who wish to leave institutional care and live in social accommodation have nowhere to go—they are not entitled to social housing (personal communication, 2012).

CHILDREN WITH DISABILITIES ARE INSTITUTIONALIZED FOR COMPLEX, INTERRELATED REASONS. UNICEF (2010) noted that "there are both economic and non-economic factors that contribute to children becoming separated from their families, and their relevance depends on the country and local context" (p. 18). There has been a popular misconception that all children living in institutions are *orphans*. In fact, the vast majority have biological parents and only a small percentage are orphans (UNICEF, 2009, p. 31). UNICEF (2010) pointed out that an increasing number of children were being separated from their families. "[I]n the 10 countries for which there are comprehensive data, the Russian Federation, Ukraine, Moldova, the Republic of Macedonia and Turkmenistan [there was] a clear increase of children without parental care over time, while no country shows a declining rate" (p. 12). Another misconception is that many children in institutions have been *abandoned*, implying that they were deserted by their parents. UNICEF (2010) found that this was often not the case (p. 25). Mulheir (2012) argued that the misconception may have arisen from a broad definition of abandonment in some countries that allowed a child to be declared abandoned if a parent had shown a *lack of interest* for a period of months. Parents' apparent lack of interest may have had more to do with poverty and other social issues (p. 121).

Parents may also place their children in institutions because they think this is best for their children given their circumstances. The Innocenti report commented that these parents' reasoning has been "partly due to a residual trust in these institutions, on the part of both the population at large and policy-makers, and lack of awareness of the potential harm of residential care for a child's development." However, "it is also due to the absence of, or incomplete reforms in, social protection and social services for families under stress", as well as "the absence of preventive measures that could help stem the flow of children into institutions and also facilitate reunification of children in institutions with their families" (UNICEF, 2009, p. 3). It must be noted that children with disabilities can also in effect be institutionalized while living with their families, if they are not receiving appropriate services and are excluded from education. Moreover, the tendency to exclude children living with their families from any statistics means that it is not possible to assess the real level and type of services needed.

2.4 HUMAN RIGHTS ABUSES WITHIN AND RELATED TO INSTITUTIONS

Numerous reports[9], by international and European human rights bodies and non-governmental organizations, document the poor living conditions and abusive treatment to which many residents are subjected in institutions. In an interim report to the United Nations General Assembly, Manfred Nowak, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment for the UN Commission on Human Rights, highlighted his grave concerns about the poor treatment of people with disabilities:

> *Persons with disabilities are often segregated from society in institutions, including prisons, social care centers, orphanages and mental health institutions. They are deprived of their liberty for*

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[9] See, for example, Annex 2 of the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care, 2012, available at: http://deinstitutionalisationguide.eu/wp-content/uploads/2012/11/Toolkit-11-02-2012-final-WEB.pdf

> *long periods of time including what may amount to a lifelong experience, either against their will or without their free and informed consent. Inside these institutions, persons with disabilities are frequently subjected to unspeakable indignities, neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence. (United Nations General Assembly, 2008, p. 8)*

The Council of Europe (2004) also expressed serious concern about unacceptable conditions found in institutions in the CoE Member States, such as cases where "fundamental means necessary to support life (food, warmth, shelter) have not been supplied, as a result of which patients have been reported to have died from malnutrition and hypothermia" (p. 21). For example, in a recent case, *Stanev v Bulgaria* (2011), the European Court of Human Rights found that the complainant's living conditions in a Bulgarian social care home—insufficient and poor quality food; inadequate heating; and unhygienic, dilapidated bathrooms where toilets were "in an execrable state and access…was dangerous"—amounted to degrading treatment and were thus a violation of Article 3 of the European Convention on Human Rights (p. 49).

Human rights violations found in institutions in E&E countries include: poor material conditions, overcrowding, insufficient sanitary facilities, an inadequate level of individual treatment, insufficient preparation of residents for future independence, lack of access to education and healthcare, an inadequate number of qualified staff to attend a large number of residents, prolonged residence, inappropriate use of seclusion, and insufficient maintenance of contact between residents and their families which often leads to a complete break of communications with residents' biological families and close relatives (Velichkovski and Chichevalieva, 2010 p. 23; EC, 2012c, p. 16; UNICEF, 2012, p. 29 and p. 99; Institution of Human Rights Ombudsmen of Bosnia and Herzegovina, 2009).

Some countries' human rights ombudspersons are shedding light on problems in institutional care. For example, The Public Defender of Georgia (2010) reported "systemic and individual human rights violations" in, among others, institutions for orphans and children with disabilities. These include ill treatment; lack of medical, psychological, and social rehabilitation programs; lack of medical assistance; isolation and inaccessibility, including confinement of residents to their bedrooms (p. 7). The most recent report on the status of children in care institutions (Public Defender of Georgia, 2012) noted improvements but raised concerns about "violence against children, ill-treatment and child neglect" (p. 6).

Such human rights violations result in children and adults with disabilities not receiving the care or support that they need and affect them long into the future. Public policies and cultural norms that disempower people with disabilities place them at great disadvantage or block their ability to control their lives altogether.

2.4.1 PUBLIC POLICIES AND CULTURAL NORMS

Laws, regulations, and social norms facilitate and perpetuate human rights violations of people with disabilities.

Guardianship. The system of guardianship used in many countries in the region authorizes guardians to make decisions on behalf of adults deemed to lack capacity. These systems infringe Article 12 of the CRPD—equal recognition before the law (Office of the High Commissioner for Human Rights [OHCHR], 2009, p. 14; Council of Europe, 2012, p. 19). Of particular concern is that such systems allow the guardian to arrange for the person subject to guardianship to be admitted to an institution without that person's consent (OHCHR, 2011, p. 13).

> *There is a close link between guardianship and institutionalization, as many adults are placed in long-stay institutions or hospitals by their legally appointed guardians against their will or through the lack of informed consent. Studies also show that guardianship can be used by*

> *families to "remove and place" unwanted family members with mental health problems in institutions. (European Expert Group, 2012, p. 77)*

Prolonged institutionalization. Recent reports from human rights bodies and comments from study respondents have highlighted the length of time people with disabilities live in institutions. For example, the Helsinki Committee (2009) studied two institutions for children and two institutions for adults in Serbia and found that inadequate living conditions, understaffing, staff without appropriate training, and inadequate occupational training meant that residents "will remain lifelong hostages to institutionalized protection…lacking fundamental living skills," and with little or no contact to the outside community (p. 5).[10] Analysis of TransMonEE data indicates that children with disabilities are the last group of children to be considered for alternative care.[11]

It is rather common that the only way many children and adults with disabilities exit institutions in the E&E region is by dying (People in Need, 2012, p. 156; Moldova personal communication, 2012; Serbia personal communication, 2012; Russia personal communication, 2012). Once children enter, they usually never leave the institutional care system and move from institution to institution.

Gender disparities in institutionalization. Disparities in admissions of men, women, girls, and boys to institutions and discharge back into the community persist throughout the region. However, there is not a region-wide trend and trends sometimes vary within a country based on whether the data are from private or public institutions (People in Need, 2012; Albania personal communication, 2012). Research in Armenia identified significant differences between the treatment of girls and boys with disabilities, with differences most prevalent in regional towns (UNICEF, 2012, p. 14–16). Boys received more visits from family members (23 percent of the boys were visited by their parents once a week or month vs. 15 percent of girls), and boys visited home more frequently than girls (among the 10 percent of children who spend holidays at home, roughly 2/3 were boys and 1/3 were girls). Girls with disabilities were consistently more likely than boys to be out of school and were more likely to be taken to orphanages.

It appears that there is a gender gap in Azerbaijan with regard to deinstitutionalization. UNICEF Azerbaijan (2011) reported that the gender distribution of deinstitutionalized differed significantly based on whether they had a disability. Of children without disabilities who were deinstitutionalized, 55 percent were boys and 45 were percent girls, compared to children with disabilities, of whom 82 percent were boys and 18 percent were girls. This trend is related to existing gender roles and biases in society. Families tend not to let their community know that they have a daughter with a disability and place a daughter in an institution to hide her from others. This pattern leads to abandonment, and male children have better chances of being reunited with their families than female children (p. 39).

These findings are in line with the overall situation of women with disabilities in the E&E region. Women are found to be more isolated than men with disabilities, because of stigma and lack of accessibility. Due to discriminatory family structures and gender violence inherent in the patriarchal systems in some of the countries, many women with disabilities are doubly marginalized (USAID, 2012, p. iv).

2.4.2 THE PERMANENT NEGATIVE EFFECTS OF INSTITUTIONALIZATION

The serious and long-standing adverse impact of institutionalization on individuals is well known (OHCHR, 2012). The *Common European Guidelines* summarize this impact on adults:

> *The institutional environment has, in itself, been shown to create additional disabilities that can stay with a person for the rest of their life. The lack of a personal life, lack of autonomy and a*

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[10] See also Disability Rights International (2007) and (2012), and European Committee for the Prevention of Torture (2009).

[11] TransMonEE Database, see: http://www.transmonee.org/Gallery_en/7_Children_with_and_without_disabilities_in_residential_care.htm [last accessed on 12 November 2012]

> *lack of respect for one's personal integrity can hamper an individual's emotional and social development.…'social deprivation' and 'taught helplessness'…describe the psychological effects of living in an institution. Language and intellectual development are…affected and institutionalization can lead to various mental health problems, including aggressiveness and depression. (European Expert Group, 2012, p. 49)*

Additional negative effects on children include physical and psychological damage and disease caused by isolation, inactivity, and poor hygiene.[12] It is a "well-documented fact" that "children develop 'disabilities' during their stay in institutions" because they lack stimulation and personal attention over extended periods and have limited family contact (UNICEF, 2010, p. 29). "Children in residential institutions face higher chances of having poor health, physical underdevelopment, motor skill delays, hearing and vision problems, reduced cognitive and social ability.…[and] a risk of bullying and abuse" (UNICEF, 2012, p. 99).

There is a growing body of scientific research confirming the largely irreversible effects of institutionalization on young children. "[R]ecent research…found significant impairment of brain development among infants raised in institutions, with the first six months of life being the most crucial. Those who remained longer…recovered only partially and demonstrated continued developmental and emotional difficulties throughout…childhood and adolescence" (Mulheir, 2012, p. 117–137). The negative impact of institutionalization on children becomes more publicly evident as they grow into adults. In Russia, for example, of children who spent their childhood in institutions, 20 percent had criminal records, 14 percent were involved in prostitution, and 10 percent committed suicide (Mulheir, 2012, p. 120).

2.5 CONCLUSION: THE IMPERATIVE TO DEVELOP ALTERNATIVES TO INSTITUTIONAL CARE

Institutionalization is an inherent violation of an individual's right to live and participate in community life. Human rights abuses that occur in institutions and the adverse effects of institutionalization are compelling reasons for ensuring that alternative forms of care are available. Chapter 3 identifies the actions that *need to be taken* by governments in the region to move from institutional care to community living, and Chapter 4 reviews the actions that *have been tak*en to date.

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[12] See WHO, 2012; Browne, 2009; and USAID, 2008.

3. FRAMEWORK FOR PROMOTING COMMUNITY LIVING

All people with disabilities in every E&E country have a right to live in community, and yet, for many reasons, institutionalization remains a common form of "care," in spite of the clear evidence that it fosters abuse and has many long-term negative effects. The development of sustainable alternatives to institutionalization may be guided by advice from the CEG. This Chapter sets out the actions to be taken to develop community-based alternatives to institutional care and to promote the social inclusion of people with disabilities.

3.1 LEGAL AND POLICY FRAMEWORK (PILLAR 1)

3.1.1 MAKE THE CASE FOR DEVELOPING COMMUNITY-BASED ALTERNATIVES TO INSTITUTIONS (CEG1)

To date, governments have given little, if any, attention to developing alternatives to institutional care. There appear to be two significant reasons: (a) a low level of concern about work that is not regarded as a priority in society and (b) a high level of anxiety about the cost of funding a complex process for developing alternative services. The stigma attached to disability and the prejudice and discrimination against people with disabilities contribute to this inattention. In the absence of strong advocacy, governments tend to ignore the issue completely or take the minimum action necessary when compelled to do so. Therefore, advocates must make the case that deinstitutionalization is beneficial to society and a better use of public resources.

So that the long-standing "broad political commitment…for transition from institutional to community-based care for all user groups" (European Expert Group, 2012, p. 34) translates into action, making the case involves demonstrating that:

- Institutionalization is not an acceptable practice according to people with disabilities, their families and advocates.
- Human rights abuses are endemic in institutions.
- Institutionalization can lead to serious and often long-term adverse consequences for persons of all age groups, particularly children.
- Institutionalization contravenes the right to community living.
- Provision of community-based services is a better and more effective use of public resources than institutionalization.
- Once living in the community with the needed support, many disabled people can become active members of society as workers and consumers, in addition to contributing to the diversity of their communities.
- Development of community-based services for people with disabilities and promoting accessibility of the built environment and services can benefit the rest of society, including older people and parents with small children.

Community-based services are a better use of resources. While the cost implications of the deinstitutionalization process will be a significant factor for governments, research shows that providing community-based services is a better use of resources. In 2004, the American Association on Intellectual and Developmental Disabilities et al. (2004) noted the fiscal wisdom of supporting human rights: "Public money is wisely spent when people grow, learn, become more independent, and enjoy their lives, and studies…show that people who move to the community are much more likely to do just those things" (p. 85). By 2012, however, the Common European Guidelines (European Expert Group,

2012) was able to summarize the increasing evidence that long-term savings can actually be achieved by shifting to community-based services.

> *[I]nvestment in services such as early intervention, family support, reintegration and high quality alternative care can help to prevent poor outcomes including early school leaving, unemployment, homelessness, addiction, anti-social behavior and criminality. In addition to having a positive long-term impact on children, which should be the primary consideration, such services will help save public funding in the long-term. (p. 50)*

Researchers have been demonstrating that human rights and balanced budgets are not antithetical for many years. The Deinstitutionalization and Community Living - outcomes and costs: report of a European Study (DECLOC) (Mansell et al., 2007) found that "Low-cost institutional care services are almost always delivering low-quality care" and that when community-based services successfully replace institutions "research studies…show better results for people receiving services, their families and the staff supporting them" (p. 3). Medieros et al. (2008) noted that community-based services make it easier to promote and protect basic human rights and are generally preferred by service users, without necessarily being more expensive than institutional care (p. 2). Mulheir (2012) found that "the cost of supporting a child to remain in their family is significantly lower than the cost of placing a child in residential care; whilst the outcomes are considerably better" (p. 133).

Moving to community-based services, however, does not guarantee better outcomes. Mansell et al (2007) pointed out that "it is possible to inadvertently transplant or recreate institutional care practices in new services" (p. 3). To avoid the replication of an institutional culture in community-based services, the European Coalition for Community Living (ECCL) noted that communities will have to "address how to change the culture as well as the physical environment" (ECCL, p. 18). The European Expert Group (2012) found that "institutional care is still widely perceived by countries as a cheaper option, particularly in relation to people with complex support needs, who may require 24-hour care" (p. 50). Some governments continue to invest in institutions rather than develop community-based alternatives and there has been severe criticism of the use of European Union funding to maintain systems of institutional care (ECCL, 2010). These critics have argued that such investments violate both the CRPD and EU law (OSF, 2012).

3.1.2 ASSESS THE SITUATION (CEG2)

The Common European Guidelines stress that a comprehensive, country-by-country assessment of the situation of people with disabilities is a necessary precondition for developing deinstitutionalization strategies and action plans. Such an assessment helps to ensure that real needs and challenges are addressed and that resources are used efficiently:

> *In addition to focusing on the system of long-term residential institutions…assessment should look…broadly at local contexts, detailing available resources (financial, material and human) [and] existing community-based services. Barriers to access in mainstream community services should also be examined in order to ensure the full inclusion of children, people with disabilities and older people. (European Expert Group, 2012, p. 53)*

CONDUCTING A COMPREHENSIVE ASSESSMENT

The Common European Guidelines (p. 61) suggest that an assessment must include three areas of information gathering and analysis.

System analysis. *National or regional level needs analyses* to develop strategies and action plans must (i) analyze existing barriers to inclusion in mainstream services and how social care, health care, and educational systems respond to children and adults with different support needs, and (ii) document reasons for institutionalization using questionnaires and interviews with institutionalized people and their families. *Local level needs and feasibility analyses* must collect both quantitative and qualitative data about the system of institutional care: (i) resident information, such as the type of disability, reasons for placement, and family links; and (ii) institutional information, such as the location, size, and number of admissions and discharges. Information should also be collected about the wider socio-economic and demographic trends in the population, such as the rates of poverty and social exclusion. These data will help policy makers anticipate the future needs of the population and develop community-based services accordingly. The Common European Guidelines (p. 58) list examples of both kinds of data.

Resource assessment. Assessment must document the human, financial, and material (e.g., state-owned land and buildings in which institutions are housed) resources currently available in the existing child protection, social care, health, and education systems. These data ensure that governments know what resources are already available, can plan how these can be best utilized during the deinstitutionalization process, and can anticipate what type of investments will be necessary to cover the so-called double-running costs—the cost of duplicate services during transition—both initially and over time.

Review of existing community-based services. Gathering comprehensive information about services that already exist helps countries avoid duplicating services and ensures that available resources are used efficiently. The Common European Guidelines list examples of this kind of information and suggest that governments develop a map showing how services are distributed in the region or the country.

3.1.3 DEVELOP A NATIONAL DEINSTITUTIONALIZATION STRATEGY AND ACTION PLAN (CEG3)

Experience has shown that deinstitutionalization is a sufficiently complex and lengthy process, that in most cases, developing a deinstitutionalization strategy is a necessary step (European Expert Group, 2012). Basing this work on assessment findings helps governments develop a strategy and action plan for a coordinated and systematic transfer of services and supports from institutions to the community. Mansell et al. (2007) noted that such assessment-based strategies and action plans can ensure that no one takes shortcuts in the transition process that will prove detrimental in the long run: (a) residents must not be moved from large to smaller institutions for the sake of closing the large institutions; (b) institutions must not be closed before needed community-based services are in place (failing to develop community-based alternatives risks leaving people even more vulnerable than before); and (c) people with higher support needs should be included in deinstitutionalization efforts from the very beginning "so that experience…meeting their needs is gained from the outset" (p. 103).

KEY ELEMENTS IN DEVELOPING A DEINSTITUTIONALIZATION STRATEGY AND ACTION PLAN

Involvement of children and adults with disabilities. An inclusive deinstitutionalization strategy can be developed for all user groups (e.g., children and adults with disabilities, people with psycho-social disabilities, and older people with disabilities) or separate strategies can be developed for individual user groups. Either way, it is crucial that decision-makers from all the relevant sectors, including child protection, health, education, culture, leisure, employment, disability, transport, and finance are involved in developing the strategy. Non-state actors, most importantly service users, their representative organizations and families, and service providers, should be involved from the very beginning.

Strategy development. Deinstitutionalization strategies should be developed with the aim of making community-based services available, closing institutions, and making mainstream services available and accessible to everyone. Strategies can be developed at a national or regional level and should include both measures to *prevent* institutionalization and measures to ensure that people living in institutions can be re-integrated in their families or communities and live independently in the community. The Common European Guidelines discuss several deinstitutionalization strategy components: (a) measures for preventing institutionalization and family separation, (b) social inclusion and anti-poverty measures, and (c) awareness-raising activities (p. 66). The Community for All Checklist (OSF, 2011) suggests the following eleven points.

POINTS TO INCLUDE IN A NATIONAL DEINSTITUTIONALIZATION STRATEGY:

- Statement that long-stay institutions are to close.
- Timetables including milestones for progress that can be quantified
  - Target dates for the closure of institution(s) are essential.
- Prohibition of admissions to long-stay institutions
- Description of the range of community-based services that are to be developed, with an emphasis on ensuring that people with disabilities can participate in community life
- Recognition of the need to develop clear standards for all community-based services and developing standards in close collaboration with people with disabilities and their families
- Financing and capacity building for NGOs and other community-based service providers
- Targets to move a certain number of people (or a certain percent of residents) from long-stay institutions each year
- Recognition that the development of community-based services must be based on actual needs and that needs will differ among localities
- Redirection of financing from institutions to community-based services
- Mechanisms for: (a) identifying, reviewing, and addressing cases of re-institutionalization, and (b) reflecting review outcomes in relevant legislation, policies, and practices

Action plan development. Short-term and long-term action plans can ensure that existing policies and strategies are implemented in practice. Priorities for short-term and long-term actions should be decided based on the assessment of the situation. Specific plans should be developed for each institution earmarked for closure.

POINTS TO INCLUDE IN A DEINSTITUTIONALIZATION ACTION PLAN

- Composition and role of the management and leadership team
- Activities corresponding to the goals and measures in the strategy
- Timeframe
- Responsible institutions and people
- Services that will be developed
- Costs, available resources, and funding required
- Monitoring and evaluation framework

3.1.4 ESTABLISH THE LEGAL FRAMEWORK FOR COMMUNITY-BASED SERVICES (CEG4)

A review of existing legislation and policy is needed to identify the existing laws that are blocking the inclusion of people with disabilities in society and the new laws that should be adopted to support deinstitutionalization. This review should actively involve people with disabilities and their representative organizations and be organized into the five arenas suggested by the Common European Guidelines. There is broad consensus on the arenas of the legal framework that require attention: (1) the right to live in the community, (2) access to mainstream services and facilities, (3) legal capacity and guardianship, (4) involuntary placement and involuntary treatment, and (5) provision of community-based services.

1. THE RIGHT TO LIVE IN THE COMMUNITY

Explicitly stating their right to live independently and participate in the community, in line with Article 19 of the CRPD, can contribute to ensuring that children and adults with disabilities receive the community support they need. Full compliance with the CRPD, however, depends on comprehensive government review of national laws and policies (United Nations, 2007, p. 70). Anti-discrimination legislation must address social exclusion in areas such as employment, education, and the provision of goods and services.

2. ACCESS TO MAINSTREAM SERVICES AND FACILITIES

Without accessible mainstream services, individuals can remain isolated even while living in community settings. Relevant anti-discrimination should provide for equal access of people with disabilities to social housing, education, employment, health care, transport, sports and cultural facilities, childcare, and other services or facilities benefiting their local community. Mansell et al. (2007) recommended that governments review rules for other relevant services such as planning, housing, employment, social security, and health care to ensure that people with disabilities who are supported in the community can get equal access (p. 104).

3. LEGAL CAPACITY AND GUARDIANSHIP

Legislation and regulations defining legal capacity should be reviewed for alignment with the CRPD. There is a strong link between plenary guardianship (the power to exercise all legal rights and duties on behalf of a service user) and placement in institutional care. Guardianship reform should be included in measures designed to promote deinstitutionalization. Restrictive guardianship laws should be abolished and replaced with legislation providing for supported decision-making for people with disabilities.

4. INVOLUNTARY PLACEMENT AND INVOLUNTARY TREATMENT

Compulsory placement and treatment can seriously hinder the options of people with disabilities to live in the community. The United Nations (2007) recommended that States should: (a) carefully review their laws and their operation in areas such as deprivation of liberty of persons with disabilities, including those with intellectual and psycho-social disabilities; (b) note [CRPD] requirements on independent living within the community instead of forced institutionalization or forced medical interventions; and (c) ensure that there are laws and procedures to monitor the operation of this legislation, investigate cases of abuse, and impose punitive measures (Article 16[4]). (p. 70)

5. PROVISION OF COMMUNITY-BASED SERVICES

To ensure that services are sustainable beyond initial strategies and action plans with European Union (EU) or other donor funding, countries need to establish appropriate new legal and regulatory frameworks governing delivery, access, and funding for services. The Ad Hoc Expert Group (2009) highlighted the importance of removing administrative obstacles to NGOs providing community-based services and recommended that governments (a) enact laws and regulations that support community-based services and (b) guarantee the involvement of users of services.

- "Identify legislative and administrative rules that directly or indirectly support institutionalization or block the transition to community-based care and change them to support the delivery of quality services in the community" (Ad Hoc Expert Group, 2009, p. 21). This might require: (a) removing old health and safety regulations more suited to institutions, (b) monitoring of institutions and handling of complaints, (c) ensuring that public funding is not used to build new institutions or for major renovation projects of existing institutions (with the exception of life-saving measures), (d) ensuring that relevant agencies in a local area take responsibility for providing services to all the local residents, and (e) ensuring that NGOs can be contracted to provide community-based services with the appropriate quality assurance systems in place.

- "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" (p. 21).

3.2 STRUCTURE AND TYPES OF PROGRAMMES AND SERVICES (PILLAR 2)

3.2.1 DEVELOP A RANGE OF SERVICES IN THE COMMUNITY (CEG5)

An effective deinstitutionalization strategy will respond to the needs and requirements of both people who live in institutions and people who live in the community. The Common European Guidelines (Chapter 5, p. 82.) identified services that could be developed for both user groups, all of which are critically needed given the dearth of community-based services available in the region:

a. Services that prevent family separation, such as mother and baby units, parent and child foster care placements

b. Personal assistance (PA), peer support and counseling, crisis intervention and emergency services, technical aids, and assistive technologies

c. Living arrangements, such as supported living and accessible housing

d. Alternative, family-based options for children, such as kinship care, foster care, adoption, and, if appropriate, group homes

When developing services, the Common European Guidelines suggest that countries follow principles for social services informed by current internationally accepted good practices.

BEST PRACTICES FOR DEVELOPING SOCIAL SERVICES

Full participation in the community. Services should enable people with disabilities and their families to participate in the community on an equal basis with others.

Choice and control. Access to information, advice, and advocacy should be provided to both children and adults with disabilities, so they can make informed choices about the support they receive.

Person-centered and child-centered support. Support should be tailored to individual needs and offer personal choices, and should be developed and provided with close involvement of people with disabilities and their families, where relevant.

Continuity of service delivery. Support should be provided as long as an individual needs it, based on their changing needs or preferences.

Separation of housing and support. The type and level of support should not be determined by where someone lives and individuals should be able to change their living arrangements without losing the support they receive.

Housing based in local communities. Countries should provide persons with disabilities with housing located in ordinary communities among the rest of the population, rather than on specialized campuses, village communities, or on the grounds of existing institutions.

Importance of mainstreaming. Instead of developing a parallel system of services for people with disabilities, mainstream services should be made accessible to people with different support needs wherever possible and specialized services should be developed whenever necessary.

Integration of services. Persons with disabilities living in the community are likely to access services from multiple providers (social care, housing, health, employment, education, and transportation), multiple sectors (public, private, and nonprofit), and multiple levels (local, regional, and national). Integration of services is crucial to achieve maximum coordination and effectiveness among different services for the sake of the best outcomes for service users.

3.2.2 ALLOCATE FINANCIAL, MATERIAL, AND HUMAN RESOURCES (CEG6)

Moving from institutions to community-based services will have major resource implications and will require careful planning, coordination and control from the beginning. In addition to financial resources, consideration must be given to physical assets such as buildings and the land on which institutions have been constructed. Two related human resource arenas—assessing individual service needs and workforce development needs—are discussed below in sections 3.2.3 and 3.3 respectively. The DECLOC report provides comprehensive information and presents successful strategies for replacing institutions with community-based services, with a focus on the economic issues in the transition (Mansell et al., 2007). The Common European Guidelines (p. 99) provide the following detailed advice on considerations and challenges governments need to take into account.

PLANNING STAGE

Identify hidden costs. When comparing the cost of institutional care and the cost of community-based services, take into consideration both hidden costs and the quality of service. Costs are often hidden within the informal care sector, such as the loss of employment or stress-related illnesses suffered by family members of people with disabilities, and costs within the health care and criminal justice systems.

Understand how services will be provided. Determine which needs will be addressed by which sector (social care, health care, housing, education, etc.).

Understand the current financing arrangements. What services are funded by taxation, social or private insurance, payments by services users, or by other mechanisms?

Consider how funding reaches the services. Are funds allocated directly to service providers, to commissioners, or to individual service users? Also, take into account the various welfare benefits paid to people with disabilities or their families.

Anticipate the extra costs of the transition period. *Hump costs* refer to the initial investment in new community-based services that will need to cover the cost of new housing in the community, furnishings, clothing, staff training, etc. *Double-running costs* (also called *parallel* or *transitional* costs) refer to the increased cost of running the two systems—institutions and community-based services—simultaneously. Some double-running costs are likely to remain until all the institutions are closed down. They can be dealt with by identifying transitional funding and minimized by careful management so that the process of transition is not overly long.

FUNDING

Guarantee funding for community services. When closing down institutions, it is important that their budgets be *ring-fenced* (officially guaranteed for a particular purpose) for services in the community that will serve the same group of people.

Clarify relationships between central governments and regional or local governments. Although some countries are implementing *decentralization* policies, institutional care is financed by the central government in most countries, whereas services such as day-care are financed by local or regional governments. Without central government or international donor funding, poor municipalities may not be able to create new community-based services (personal communication, 2012).

Move budgeting responsibilities toward the local level. Budgeting can be decentralized (devolved) to a regional or local level. Mansell et al. (2007) suggested that “devolved budgets and purchasing of services increase the likelihood of services responding to the assessed needs and expressed preferences of individuals” (p. 82). Whether funding is centralized or devolved, it is important that its distribution is based on the distribution of needs and agreed policy priorities.

Assess and manage entitlements. The growth of community-based services is accompanied by a diversification of funding sources, including entitlements such as social insurance (e.g., disability insurance) or social assistance (e.g., housing assistance, child care assistance, transportation subsidies, etc.) from government sources based on identified needs or conditions. Because services are funded from more budgets—housing and education sectors, as well as the social or health care systems—knowing how to assess an individual’s qualification for various forms of assistance and manage the use and coordination of an individual’s entitlements is a key challenge.

Manage changes in how services are procured. With *self-directed* or *consumer-directed* care, funds for purchasing services are provided directly to individuals in the form of *direct payments* or *personal/individual budgets*. This requires a move from block contracts to individualized procurement of services. This shift can take time and require support, ideally by peers, to help service users manage their direct payments or individual budgets.

Anticipate political and economic challenges. Local communities may be opposed to the closure of institutions out of concern for the possible loss of local jobs and negative effects on the local economy. There can also be uncertainty and disagreement about what to do with the buildings housing institutions, which may be suitable for another use or may be of no value.

3.2.3 DEVELOP INDIVIDUAL PLANS (CEG7)

The Common European Guidelines (p. 112) point out that moving from a system of institutional care to community-based support requires the involvement of persons with disabilities and a necessary change in how individual needs and preferences are assessed. People who have spent years in institutions may find it difficult to formulate their own wishes and preferences about their new life in the community. Accessible information and support, preferably provided by other people with disabilities, is essential. The key elements of a support process are individual assessment, implementation, and review. The results of the assessment need to be linked to the strategy for developing services, in order to ensure that support services are developed on the basis of individual needs and preferences, rather than individuals having to fit into existing services, whether or not those services can meet their needs. The Common European Guidelines highlight three key aspects of this individual support:

- *User involvement.* Planning involves important decisions about individual's lives, e.g., where they will live and how they wish to be supported. It is crucial that people be involved in the process, including children and adults unable to express themselves verbally who need specialized support to express their views.
- *Individual assessment.* Detailed information about a person's needs and preferences informs the development of an individual care and support plan. Assessment methods, including self-assessment, help people assess their own needs and preferences, sometimes with the help of a person they trust.
- *Individual care and support plan.* A detailed plan for the person with disabilities and his or her family and carers, describes the living arrangements and support that will be provided to the individual. The plan should formulate clear goals with specific and measurable outcomes, and should be reviewed on a regular basis to monitor progress towards the desired outcomes and make any necessary changes.

3.3 DEVELOPING HUMAN CAPACITY (PILLAR 3)

3.3.1 DEVELOP THE WORKFORCE (CEG10)

The lack of a well-trained workforce is a key obstacle to providing quality community-based services. The Common European Guidelines highlight several workforce development challenges that must be addressed in any deinstitutionalization strategy:

- *The availability of staff with the range of skills* necessary to deliver services in the community, such as occupational and speech therapists, personal assistants, etc. is the main pre-condition for developing and providing services in the community.
- *Ways of motivating current staff members and addressing their concerns* should be a part of the planning process when closing institutions. The status, pay, benefits, and working conditions of staff members must be adequate to motivate them to deliver quality support in the community.
- *The support needs of informal carers* who are likely to continue providing support, including employment-friendly policies for families wishing to combine providing care with paid employment, must be considered. Informal carers should not be required to provide all support.

A FOUR-STAGE WORKFORCE DEVELOPMENT PROCESS

Knowing what staff is available, projecting future staffing needs, including professional standards and certification requirements, and developing corresponding strategies are key components of a comprehensive planning process. Comprehensive, reliable data are essential to create a realistic picture of the people needing services and what services they need, particularly with respect to projecting staff needs. The Common European Guidelines suggest a four-stage workforce development process (p. 149).

1. *Planning*. The transition to community-based services requires a major *paradigm shift*. In institutions, doctors and nurses work alongside administrative and maintenance personnel, whereas community services require social workers, teaching assistants, and speech and occupational therapists, among others. New professions and roles are required in the community, such as personal assistants, paid and informal carers, and advocates. (See section 3.5 below.) One of the first priorities is developing a workforce strategy or human resource plan that identifies personnel requirements for both management and support personnel for the new services. Another early priority is the effective coordination between national and local strategies.

2. *Selection of personnel.* It is important that people who will be working in the new services be sufficiently trained before the services open. They should be chosen in a competitive process by selection committees involving users of services. These committees must ensure that staff members who have worked in institutions are able to change their attitudes and practices to suit their new role, in order to avoid replication of old institutional practices in new community settings.

3. *Training and re-training*. Systematic and well-coordinated training curricula, and certification based on desired staff competencies where appropriate, should include initial education, in-service training, and life-long learning to ensure that staff are adequately trained. Knowing the rights of children and people with disabilities and human rights standards, such as the UN Convention on the Rights of Persons with Disabilities and the UN Guidelines for the Alternative Care of Children, should be central elements of these curricula. Equally important is involving people with disabilities and their representative organizations in developing training materials and training staff.

4. *Developing the social work profession*. Because social work is one of the key professions involved in delivering community-based services, action must be taken to "create legislation and education programs, develop and strengthen curricula, support professional associations of social workers, develop licensing and practice standards, and raise awareness about the need for social workers" (European Expert Group, p. 153).

3.4 PERFORMANCE OUTCOMES AND MEASURES (PILLAR 4)

3.4.1 DEVELOP, MONITOR, AND EVALUATE THE QUALITY OF SERVICES (CEG9)

The Common European Guidelines emphasize that developing quality standards for services in the community, and monitoring and evaluating the quality of those services, must be a part of an overall deinstitutionalization strategy. This strategy should be closely linked with ending admissions to institutions and redirecting resources to community-based services. (See the CEG, p. 136.)

1. Define quality standards. Avoiding replication of institutional practices in community settings requires changes in how standards are set and how services are evaluated. The same standards cannot be used for institutional care and community services. New standards must focus on the human rights and quality of life outcomes of service users, rather than organizational and technical issues related to the status of health care, hygiene, and facilities of service providers. The Common European Guidelines identify several resources for defining quality standards, which should involve the central government, local/regional authorities and the service providers: (a) Voluntary European Quality Framework for Social Services (adopted by EU's Social Protection Committee), (b) Shalock's Quality of Life Framework, (c) European Principles of Excellence in Social Services (EQUASS), and (d) Quality4Children Standards for Out-of-Home Child Care in Europe.

2. Implement standards. Different levels of government (central, regional, or local), service providers, and organizations representing people with disabilities will be involved in setting and monitoring quality standards. The UNICEF and the World Bank (2003) proposals for responsibilities and actions at these different levels provide a useful framework for government planning.

3. Monitor and evaluate. Monitoring and evaluation (M&E) can ensure transparency, accountability, and control of all aspects of providing services. M&E should be built into all of the stages of deinstitutionalization and conducted in close cooperation with service users (people with disabilities), their representative organizations, and families, where relevant. The effectiveness of M&E depends on clarity about what is being monitored. For example, noting that services have excellent written policies and protocols is irrelevant if providers fail to implement them. The process of deinstitutionalization itself also requires close monitoring to ensure that problems are identified and addressed. Until the last person has left the institution, there should be close and independent monitoring of the conditions in institutional care. Efforts should be made to improve the quality of care, especially where people's health and safety are at risk. This should not, however, result in major renovation projects that will make it difficult to close the institution in the long-term.

3.5 INCREASING AWARENESS AND PARTICIPATION (PILLAR 5)

3.5.1 INCREASE AWARENESS AND PARTICIPATION (CEG8)

The success of all aspects of a deinstitutionalization strategy depends on increasing awareness of the rights of people with disabilities, promoting communication, and ensuring the active involvement of people with disabilities in planning and implementing laws and policies that affect them. The CEG (p. 125) stress support for individuals and communities during the transition process.

Prepare individuals, families, and the community. The transition to the community is not limited to physically moving individuals from one living arrangement to another. This transition should be carefully planned so that it includes preparation for the individuals moving, their families, and the communities to which they are moving. Individual preferences, and care and support plans, play an important role in the success of this transition.

Deal with specific age group concerns. The transition for *children* should focus on building or re-building the attachment with the parent or a carer who has taken responsibility of the child. For *youth leaving care*, the focus should be on preparing their transition to independent living. The transition for *adults* should provide special attention and support for the most vulnerable. As with children, youth and adults should be familiarized with new environments, the persons providing support, and neighbors.

Build individual, family, and community capacity. The transition from institutional care to community living requires capacity building at many levels.

1. People living in institutions who have not had opportunities to develop skills for independent daily living or who have lost them over the years, will need additional support such as training and advice on personal assistance—the key to independence for many. People with disabilities, including children and people with intellectual disabilities, can and do speak up for themselves, and *self-advocacy* helps them take control of their own lives. At the same time, *peer support*—advice and assistance from people with similar experiences or backgrounds—helps them gain confidence and deal with unfamiliar situations.

2. *Training on providing better care* and *support for carers* should be given to the families of children and adults leaving institutions. Respite or emergency care gives family carers a break "to ensure the quality of care provided by them as well as to preserve their own quality of life" (Ad Hoc Expert Group, 2009, p. 21).

3. *Working with communities on careful planning and implementation* is needed to facilitate the full inclusion of people with disabilities in the community. Awareness-raising activities can prevent negative attitudes and resistance to people with disabilities moving into a neighborhood or attending local schools.

ESTABLISHING INNOVATIVE SERVICES THAT DEMONSTRATE BENEFICIAL OUTCOMES

- Fund the development of independent and supported living in the community, using ordinary housing and providing the level of staff support each individual needs.
- Ensure that demonstration projects reflect best practice in how they are set up and run.
- Ensure that demonstration projects (a) bring people back home from institutions and (b) serve local people on *waiting lists*, so that members of the community in which services are developed are more likely to be supportive and helpful.
- Ensure that demonstration projects include options for both accommodation and occupation (education, employment or other day-time activities) to increase the likelihood of success.
- Support new forms of training and professional qualification to ensure that there are sufficient staff members are available to support people well as new services develop.
- Monitor the quality and costs of new services.
- Create arrangements for contracting for innovative local services, so that existing rules designed for institutional care systems are waived or modified to permit development of services in the community.

(Mansell et al., 2007, p. 103)

3.6 CONCLUSION: GOOD PRACTICES EMPOWER THE SHIFT FROM THEORY TO PRACTICE

Chapter 3 has outlined the key elements of a transition from institutional care to community-based services, based on research and good practice. All of these elements must be taken into account if countries are to replace long-stay residential institutions for people with disabilities with quality alternatives in the community. Chapter 4 assesses what progress has been made to date and what challenges remain. Chapter 5 uses the findings and conclusions of this assessment as the basis for practical recommendations to USAID Missions.

4. THE STATUS OF PROGRESS AND CHALLENGES IN THE TRANSITION TO COMMUNITY LIVING

Chapter 4 considers the main challenges in the E&E region for effecting the transition from institutional care to community-based services that promote the social inclusion of people with disabilities and the extent to which progress has been made. It also considers the role of international donors in facilitating this transition to community living. The discussion is based on information obtained from official documents and on information from NGOs working with people with disabilities in the region.

4.1 LEGAL AND POLICY FRAMEWORK (PILLAR 1)

4.1.1 MAKING THE CASE FOR DEVELOPING COMMUNITY-BASED ALTERNATIVES TO INSTITUTIONS

Despite the wide consensus on the need for action to ensure the shift from institutional care to the provision of community-based services, this has yet to be translated into practice. In the E&E region, institutionalization remains the predominant form of care for people with disabilities. Setting out the arguments for the necessary reforms will often be the first step in the process of moving from institutional care to community living. The following four interrelated issues will need to be addressed.

THE LACK OF GOVERNMENT COMMITMENT

The lack of political will and government commitment to develop community-based alternatives to institutional care is often cited as one of the main reasons for failing to reduce the number of people placed in institutions. In **Serbia**, for example, the "master plan" for transformation of institutions for children does not explicitly mention deinstitutionalization. In addition, despite the Government's commitments to work towards deinstitutionalization, "there is no clear strategy nor has the closure of institutions been set as one of the goals" (personal communication, 2012).

THE FAILURE TO RECOGNIZE THE NEED FOR REFORM

Related to the lack of political will is the lack of information on the situation of children and adults with disabilities living in institutions in the region. This *obscures the need for reform, which in turn means that governments do not regard the development of community-based alternatives to institutionalization as an important, or necessary step.* For example, in **Russia**, while there has been a clear policy movement toward providing non-residential support and services for children, there has been little change in the situation of children with disabilities, who make up 50 percent of children in all residential care (Rogers, 2012). In the **Republic of Macedonia**, it is noted that failure to implement various laws related to the rights of persons with disabilities hinders progress. (Velichkovski and Chichevalieva, 2010, p.12).

LACK OF COORDINATION ACROSS MINISTRIES AND CENTRAL AND LOCAL GOVERNMENT

Problems of coordination and cooperation among central government ministries and between the central and local governments hinder the development of alternatives to institutionalization and the work to prevent new admissions to institutions. This is a particular problem in **Albania, Azerbaijan, Belarus, Georgia and Serbia** (EC, 2012; personal communication, 2012).

LOW LEVEL OF ACCOUNTABILITY AND RESPONSIBILITY OF LOCAL GOVERNMENT

The DECLOC report notes the importance of the local government agencies taking responsibility for serving people with disabilities in their local area (2007, p. 101). The lack of accountability by the local government has been reported in **Albania**, where it was noted that "the funds are there" but are used neither effectively nor efficiently (personal communication, 2012).

4.1.2 ASSESSING THE CURRENT SITUATION OF PEOPLE WITH DISABILITIES

LACK OF INFORMATION ON THE SITUATION OF PEOPLE WITH DISABILITIES

There are significant difficulties in obtaining reliable information about people with disabilities, including those placed in institutions, in the E&E region. Although more is known about children with disabilities than about adults with disabilities, the available information is often neither comprehensive nor consistent, from year to year and from region to region.

Multiple studies have addressed the need for better information and analysis. USAID (2009a) observed that "more rigorous data collection and reporting practices would improve the knowledge about disability in the region and increase the likelihood that effective services can be delivered" (p. 33). Innocenti (2009) wrote that "it is important that statistics on children in institutions are disaggregated in order to identify the different types of institutions (large residential, boarding school, family-type), and the reasons for placement" (p. 32).

Without comprehensive and accurate information, it is not possible to develop services and supports that are responsive to the needs of people with disabilities. Thus, Mansell et al. (2007) argued that "The data set needs to include sufficient information about the people served (gender, ethnicity, primary disability) to enable States to ensure that everyone is benefiting from the transition away from institutions to better alternatives in the community" (p. 94). Rogers (2010) asserted that "It is very important to use factors which may lead to family breakdown in social services planning and development, so [services] correspond to the children's and the families' needs" (p. 2).

4.1.3 DEVELOPING A STRATEGY AND AN ACTION PLAN

With one exception, none of the countries in the region has a comprehensive strategy for planning and implementing a deinstitutionalization process for all people with disabilities (children, adults and people with mental health problems). Although the **Republic of Macedonia** is exceptional in that it has both a National Strategy of Deinstitutionalization in the System of Social Protection 2008–2018 (adopted in 2008) and an Action Plan for the first phase of the strategy, there are major concerns about the lack of progress in implementing this strategy (EC, 2012c, p. 46). The EC also noted that there had been no progress the implementation of Macedonia's action plan to create community-based mental healthcare as an alternative to institutions.

LIMITED PROGRESS WITH STRATEGIES AND ACTION PLANS FOR CHILD-CARE REFORM

In relation to children, strategies and action plans have been adopted in **Armenia, Azerbaijan, Georgia, and Moldova**. However, the implementation of these strategies and action plans are problematic in **Armenia, Azerbaijan, and Georgia**. In **Armenia**, as part of the National Plan of Action for Protection of Children for 2004 – 2015 approximately 4,000 children were reintegrated with their families in 2007 following the restructuring of 17 boarding schools, but no plan was offered "for how, and within what timetable to close, transform or downscale the remaining residential care institutions" (UNICEF Armenia, 2010, p. 7). **Azerbaijan** adopted a State Program on Deinstitutionalization and Alternative Care 2006-2015 in March 2006, but its actions are vague, without specific measurable targets (personal communication, 2012). Moreover, although a Master Plan of Transformation for children in institutions was approved in 2010 and plans for transforming seven institutions were completed in early 2011, there has been no action since then. In **Georgia**, the 2008-2011 Action Plan for Child Welfare Reform, which included a large-scale deinstitutionalization process was implemented by the end of 2011. However, two specific issues were noted. The Public Defender of Georgia (2012) reported that the reform has led to most of the children being transferred to "small family type homes (8 to 10 children per each home)" (p. 7), which do not necessarily respond to their needs. One respondent suggested that children with severe disabilities remain in institutions and are then transferred to adult institutions (personal communication, 2012). Therefore, children with the most complex needs remain institutionalized for life.

In **Bosnia and Herzegovina and Serbia**, the EC (2012b and f) reported some progress in developing alternatives to institutional care for children with disabilities. In **Serbia**, for example, young people with disabilities have been given priority in the process of developing family-based forms of care, and this priority is formally reflected in the law of April 2011 (personal communication, 2012). However, institutionalization of children with disabilities remains of concern in **Albania** (EC, 2013a, p. 44), **Bosnia and Herzegovina** (EC, 2012, p. 18) and **Serbia** (EC, 2013f, p. 45). Rogers (2012) reported that in **Russia**, although models of good practice have started to emerge, deinstitutionalization of services for children with disabilities has progressed very slowly. Greater focus is needed at the national level on ensuring that children with disabilities are not left out of the reforms and that the campaign for inclusive education spreads to all parts of Russia. In addition, the reforms have not been as rapid as needed for infants and babies, given how damaging institutional care is for younger children.

In the absence of clear strategies and action plans for the development of community-based alternatives, institutions will remain and people with disabilities will continue to be institutionalized. For example, when reviewing **Ukraine's** compliance with the CRC, the Committee on the Rights of the Child (2011a) noted the drastic increase in the number of children deprived of their family environment due to poverty, unemployment, breakdown of families, and labor migration. In spite of the approval of the State Programme for reforming the child protection system and increased efforts to develop further a system of alternative care, it was concerned that, "in the absence of a clear reform strategy, focus has not yet shifted towards deinstitutionalization [and] the Committee is concerned at the large number of children who remain in residential care and at the absence of services for family reintegration" (p. 11).

Moldova provides a positive example of concrete action being taken to plan and implement childcare reform. The government has "initiated the deinstitutionalization reform" by approving the National Strategy and Action Plan on the reform of the residential childcare for 2007–2012 (personal communication, 2012). The Ministry of Education established a Coordination Council for the reform of the residential child care system and inclusive education development in 2010 and currently is revising an action plan for 2012 to 2015, which stipulates the reorganization of 22 residential care institutions. Furthermore, "The Program for the Development of Inclusive Education for 2011–2020 was approved in July 2011. The document sets a concept framework for inclusive education based on the need to adapt the national education system to meet the various needs of children arising from their diversity. The Regulations on fund reallocation from residential care institutions to community-based social services has been approved recently in order to ensure the sustainability of the reform" (personal communication, 2012). However, there is no action plan for the closure of institutions under the Ministry of Health and the Ministry of Labor, Social Protection and Family (personal communication, 2012).

INADEQUATE STRATEGIES FOR PEOPLE WITH DISABILITIES OR LACK OF IMPLEMENTATION

People in Need (2012) found that in **Kosovo**, although the National Action Plan for People with Disabilities 2009 – 2011 refers to deinstitutionalization, it lacks specific actions for developing alternatives for institutional care. In spite of reforms intended to close an institution for people with disabilities (the Special Institute in Shtime), new residents continue to be admitted. Furthermore, although a network of community-based homes has been developed for people with intellectual disabilities, there are concerns that residents have not been helped toward independent living and continue to have limited contact with the outside world (People in Need, 2012, p. 112). More recently, in August 2013, the government adopted a new strategy for the rights of people with disabilities 2013 – 2023 and an action plan 2013 – 2015 (EC, 2013d, p. 16).

In the **Republic of Macedonia**, the EC reported limited progress in the implementation of the national strategy on equal rights for people with disabilities 2010 – 2018 (EC, 2013c, p. 36). With regard to people with mental health problems, there has been no progress in developing community-based services as an alternative to institutions (p. 55). A working group was set up, however, to draft a national strategy on mental health covering the period until 2020 (p. 55).

Problems with implementation of the national strategy have also been noted in relation to **Albania** (EC, 2012, p.19), although several developments have taken place since. The National Action Plan 2012 – 2021 was published in November 2012, followed by the ratification of the CRPD at the beginning of 2013 (EC, 2013a, p. 34). In February 2013, Albania adopted a national action plan for the development of mental health services 2013 – 2022 (p. 53). Despite this, the EC reported that "there has been no progress towards the development of community-based mental health services" (p. 54).

Though training was given to social workers in **Montenegro**, the process of transition from institutional to community-based care is considered to be at an "embryonic stage" (EC, 2012e, p. 41). In **Armenia**, despite progress made with some institutions, the government "has not yet developed a plan for how, and within what timetable to close, transform or downscale the remaining residential care institutions, an important operational step which has been taken by a few other countries in the CEE/CIS" (UNICEF Armenia, 2010, p. 7). In **Serbia**, while national policy refers to the transfer of institutional care, it also provides for the establishment of new institutions. "Although there is some kind of commitment of the government to work toward deinstitutionalization (DI), a strategy has not been clearly established nor closure of institutions has been set as a goal of transformation" (personal communication, 2012).

4.1.4 ESTABLISHING THE LEGAL FRAMEWORK FOR COMMUNITY-BASED SERVICES

A review of existing legislation and policies should identify which laws and policies need to be adopted to support the process of deinstitutionalization and to address any remaining legal and administrative barriers to providing community-based supports to persons with disabilities. It will be important to ascertain, for example, whether people with disabilities or parents of children with disabilities are able to influence or contest a decision about placement in institutional care (personal communication, 2012).

LEGAL REFORMS UNDERTAKEN IN THE REGION

Relevant legal reforms are underway in some of the countries in the E&E region. In **Belarus**, legislative bodies are preparing changes to the existing legislation, including a list of free services available to persons with disabilities. At present, however, the provision of social services to persons with disabilities, especially those living in rural areas, is insufficient (personal communication, 2012).

The Government of **Moldova** adopted the National Program for the creation of an integrated social service system for 2008–2012, which is "expected to rapidly expand community-based and specialized social services and significantly improve the efficiency of highly specialized social services" (personal communication, 2012). This has been followed by the Framework Regulation and Minimum Quality Standards for specialized new community-based social services for persons with disabilities, which includes "Supported Living" for adults with intellectual disabilities (personal communication, 2012).

In **Russia**, "a precedent has been set in [St. Petersburg City] for a 'salary' payment to parents who are full-time carers for their child or children with multiple disabilities. Three other regions are currently considering…similar legislation and there is the possibility of it being considered at the Federal level." Furthermore, the Ministry of Education strategy has clearly stated goals for extending the reach of education to children with disabilities. The strategy provides for making schools physically accessible and for the development of resource centers in every region to help them move towards inclusive education (Rogers, 2012, p. 2).

In **Serbia**, the Law against Discrimination of Persons with Disabilities, adopted in 2006, bans all kind of discrimination of persons with disabilities, including their segregation. The Law on Fundamentals of Education, adopted in 2009, supports inclusion of children with disabilities and establishes commission for assessment of additional educational needs of a child, such as assistance, assistive devices, health issues, and social benefits (personal communication, 2012). A number of legislative developments were reported by the EC in 2013: (a) the Law on the Protection of Rights of Persons with a Mental Disability introduced basic legal safeguards for those involuntarily placed in psychiatric institutions (2013f, p. 43), (b) implementing legislation was adopted under the Law on Social Welfare (p. 35), (c) amendments were made to the Law on Professional Rehabilitation and Employment of Persons with Disabilities (p. 35) and (d) the strategy on the fight against discrimination 2013 – 2018 was adopted (p. 36).

In **Montenegro**, a new law on social and child protection was adopted in May 2013, and guidelines were developed for the inclusion of children with disabilities into the mainstream education (EC, 2013e, p. 32).

REVIEWS OF COMPLIANCE WITH THE CRPD

Reviews of legislation have occurred in **Armenia, Azerbaijan, Moldova, and Serbia** (personal communication, 2012). In **Moldova**, they concern laws on the legal capacity and social inclusion of people with disabilities. In **Serbia**, working groups have been established to consider issues relating to legal capacity and deprivation of liberty.

SHORTCOMINGS IN LAWS AND POLICIES

Serious shortcomings to laws and policies relevant to the development of community-based alternatives to the institutionalization of people with disabilities and the promotion of their social inclusion are highlighted as follows:

In **Albania** the framework law on the rights of persons with disabilities is yet to be adopted (EC, 2012, p.19).

Azerbaijan's Disability Prevention and Disabled People's Social Protection Act of 1992 (Social Services Initiative, 2010) is considered to be outdated. Although NGOs have worked with ministerial partners to draft new policies and legislation, to date none have been approved. The Social Services Act of 2011 permits individuals and legal entities to provide community-based services, but does not specify how. The State Program on Deinstitutionalization and Alternative Care 2006–2015 was adopted in March 2006 but only covers institutions for children (personal communication, 2012).

In **Bosnia and Herzegovina**, people with disabilities are still excluded from the categories protected against discrimination by the anti-discrimination law (EC, 2013b, p. 18).

In **Georgia**, the relevant law is spread among different statutes and there are significant gaps. People with disabilities are insufficiently aware of their rights and, in practice, reintegration into society, education, employment, and community integration of people with disabilities are weak (personal communication, 2012).

In the **Republic of Macedonia**, it is argued that the legal framework for the protection of rights of persons with disabilities is incomplete (Velichkovski and Chichevalieva, 2010, p. 12). Although a new Law on Child Protection was adopted, children with disabilities "remain the most vulnerable group, and their social inclusion continues to be hampered by stigma, discrimination, and a lack of appropriate infrastructure and social services" (EC, 2013c, p. 45).

In **Montenegro**, the EC noted that the Law on Prohibition of Discrimination of People with Disabilities still presents shortcomings (EC, 2012e, p. 14). The EC also noted that although the government had adopted an Action Plan for the Integration of Persons with Disabilities 2012–2013, the laws on social and child welfare are still missing (p. 41).

Problems reported in **Russia** include "continued inter-sectoral divisions at all levels; lack of clearly stated Federal level policy; lack of guidance in legislation around defining 'inadequate parental care', 'threat to life and health', and other key parts of the legislative framework" (Rogers, 2012, p. 5).

In **Serbia**, although the 2011 Law on Social Welfare recognizes a wide range of services, it is very broad and many services are not yet clearly defined because by-laws have not been adopted. Furthermore, the law sets very high eligibility criteria for certain social benefits for families of children with disabilities, and is unclear about the ways in which families are to be supported (personal communication, 2012). Although the law provides that children under three years of age cannot be placed in institutional care except in cases of particularly justified reasons, and children cannot spend more than two months there, except with the approval of the relevant ministry, the expression "particularly justified reasons" is ambiguous. The concern is that this will permit arbitrary decisions on whether a child needs institutional care (People in Need, 2012, p. 151).

FAILURE TO REVIEW GUARDIANSHIP LAWS

Respondents in **Georgia, Kosovo, and Moldova**, and reports from **Russia and Serbia** identified inadequate guardianship legislation as a significant legal barrier to community living.

The detrimental impact of guardianship is illustrated by the report on **Kosovo** by People in Need (2012), which notes that people in institutions who have been deprived of legal capacity are not legally entitled to initiate the procedure for being released from the institution (p. 97). Similar points were raised by the UN Human Rights Committee (HRC) (2009) in its observations on **Russia**. The HRC expressed concern about the significant number of persons with mental disabilities deprived of legal capacity, and the "apparent lack of adequate procedural and substantive safeguards against disproportionate restrictions in their enjoyment of rights" under the International Covenant on Civil and Political Rights (ICCPR). They cited the absence of procedural safeguards and inability to appeal against the judicial decision, based on "the mere existence of a psychiatric diagnosis to deprive an individual of his/her legal capacity", or against the decision to institutionalize the individual as particularly problematic. Furthermore, HRC noted that those without legal capacity have no legal recourse to challenge other violations of their human rights in the institution. (p. 9)

4.2 STRUCTURE AND TYPES OF PROGRAMMES AND SERVICES (PILLAR 2)

Study findings relate to two of the three action points of Pillar 2 – developing a range of services in the community and allocating financial, material and human resources. Information on developing individual plans was not available.

4.2.1 DEVELOPING A RANGE OF SERVICES IN THE COMMUNITY

The WHO (2010) observed that the slow progress of countries in Central and Eastern Europe towards community living in the 1980s and 1990s was caused by a number of factors: worsening economic conditions, political instability, and in some countries, war or ethnic conflict. Families with children and adults with disabilities "were…often trapped in chronic poverty and forced to abandon vulnerable family members to institutions" (p. 9). This led to an increase in the number of children and adults in institutions and established institutional care as the prevalent type of care for children, young people, and adults with disabilities by the end of the 1990s.

The present study has identified several factors that inhibit the development of a range of services that support community living. They are: (a) lack of clarity about the mechanisms to replace institutionalization, (b) lack of knowledge on how to develop services, and (c) lack of control by service users over services and choices about where and how to receive support. These overarching factors are considered first, followed by specific concerns in relation to access to community-based services.

LACK OF CLARITY ABOUT THE MECHANISMS TO REPLACE INSTITUTIONALIZATION

The Council of Europe Commissioner for Human Rights (2011) indicated that while exclusion and segregation of people with disabilities continue, steps are being taken in some countries to remedy this situation. Challenges accompany these attempts, however. "Though governments increasingly recognize the inevitability of deinstitutionalisation, there is less clarity with regard to the mechanisms that replace institutionalisation and what would constitute a human rights-based response" (p. 9). The World Report on Disability echoed the same concern: "For many people with intellectual impairments and mental health conditions, the main community service is attendance at a day center [that] often fails to provide an entry to employment, produce greater satisfaction, or deliver meaningful adult activities (WHO, 2011, p.145). UNICEF pointed to the slow development of family-based alternative care in the CEE/CIS region and the impact on children. While most countries in the region have begun developing foster care and guardianship, for example, UNICEF (2010) warned against a negative trend:

> *Family-based alternative care is not necessarily being provided as a positive alternative to residential care, but rather in response to poor prevention policies that lead to large numbers of children needing alternative care. It is being used as a long-term measure, rather than as a temporary measure until longer-term solutions—either reunification with the biological family or adoption—are found. In many countries foster care, guardianship or other family type care are still underdeveloped, and more often than not informal kinship care arrangements are widespread but not necessarily well documented and supported by the state. (p. 36)*

LACK OF KNOWLEDGE OF HOW TO DEVELOP SERVICES

Several of this study's respondents indicated that insufficient knowledge and expertise within governments in the region to plan and manage a deinstitutionalization process is a major concern. Previous studies have noted the same challenge and the value of international co-operation between States in addressing it, in line with Article 32 of the CRPD (International Cooperation).

LACK OF CONTROL BY SERVICE USERS OVER SERVICES AND CHOICES ABOUT WHERE AND HOW TO RECEIVE SUPPORT

The WHO (2011) report indicates that support services are often only available to those in sheltered housing projects or group homes and institutions, not individuals living in their own homes. Where community-based services are available, people with disabilities often lack sufficient control over these services, and are denied the choice of where and how they receive support (p. 145).

CONCERNS ABOUT ACCESS TO COMMUNITY-BASED SERVICES

Although community-based services are lacking throughout the E&E region, some have been developed. Respondents to this study provided examples from **Albania, Azerbaijan, Bosnia and Herzegovina,** the **Republic of Macedonia, Moldova, Serbia, and Russia** (personal communication, 2012). These are set out in the table below. While the existence of community-based services is positive, such examples are rare in this region. Furthermore, many such services are provided by NGOs that have limited capacity, as a result of which their services are available only to a small group of people. In addition to the scarcity of specialized services for people with disabilities, two further significant barriers prevent people with disabilities from living in the community. These are: (a) failure to provide inclusive education and (b) inadequate access to mainstream services.

FAILURE TO PROVIDE INCLUSIVE EDUCATION

The integration of children with disabilities into the public education system remains an issue throughout the region. Some progress has been reported in **Albania**, where the Law on Pre-University Education provides for assistant teachers for children with disabilities (EC, 2012a, p. 20), **Moldova**, where "in the last two years 36 Resource Centers for Inclusive Education have been opened in 16 of the 35 rayons and 9 Psycho-pedagogical Services have been developed in 9 rayons" (personal communication, 2012) and in **Belarus**, where some schools and classes are integrated (personal communication, 2012). Nevertheless, the study respondent from **Moldova** noted that special schools still exist and the majority of mainstream schools are still inaccessible to children with disabilities, with only 1,604 children with disabilities (out of 14,000) benefiting from support services in 2011-12. The main barriers to inclusion are the inaccessible physical environment and teachers lacking the ability to work with children with disabilities (personal communication, 2012). Further efforts are also needed in **Albania** and **Montenegro** (EC, 2012a, p. 54 and EC, 2012e, p. 49).

INADEQUATE ACCESS TO MAINSTREAM SERVICES

Various reports have highlighted the need for action to mainstream services. For example, in **Kosovo** the EC (2012d) expressed concerns about limited access to employment, goods and services, transportation, and education, and recommended that special attention be given to persons with disabilities when designing employment policies (p. 13). In **Armenia**, UNICEF Armenia (2010) recommended "a number of new community-based social services, such as family and child support services and alternative family based substitute care services" (p. 7). In **Bosnia and Herzegovina**, moderate progress was made in improving people with disabilities' access to primary health care by establishing 60 community-based rehabilitation centers, which provide comprehensive medical services and rehabilitation (People in Need, 2012, p. 59).

EXAMPLES OF COMMUNITY-BASED SERVICES IN THE REGION

Country	Community-Based Services
Albania	Foster care has been piloted for 80 beneficiaries and supported by the State budget since April 2012 (personal communication, 2012).
Azerbaijan	Community-based support services for children with intellectual disabilities have been piloted by the Social Services Initiative and are currently becoming a part of the services provided by the Ministry of Social Welfare (personal communication, 2012).
Bosnia and Herzegovina	PA services for people with disabilities have been provided by two NGOs, one in the Federation of Bosnia and Herzegovina (FBiH) and one in the Republika Srpska (RS). In RS, the service has been recognized by the municipal authorities and incorporated into the social welfare services. Prevention of institutionalization services and deinstitutionalization of people with intellectual disabilities have been provided by an NGO, in cooperation with the Ministry of Labor and Social Policy and the Centers of Social Work. To date, the project has prevented the institutionalization of eight people and deinstitutionalized seven (People in Need, 2012). A network of community-based mental health services has been established and efforts are being made to train the staff (EC, 2013b, p. 38).
Republic of Macedonia	Foster care for children with disabilities has been developed in six locations – Skopje, Prilep, Makedonski Brod, Kocani, Krusevo, and Veles (Velichkovski and Chicevalieva, 2010, p. 20) A total of 69 people with disabilities live in group homes set up as part of the deinstitutionalization process (EC, 2013c, p. 45).

Moldova	The Keystone Human Services International Moldova Association has supported local public authorities in developing new specialized social services for people with disabilities who have left institutions. These included three community homes, two supported living units, three foster care units for children with disabilities, one shared living unit for adults with disabilities, nine mobile teams, and personal assistance and respite care services (personal communication, 2012).
Serbia	A supported living service with seven apartments for around 30 clients has been provided by the Serbian Association for Promotion of Inclusion in Belgrade (personal communication, 2012). The Center for Independent Living Serbia is an accredited trainer and provider of PA that has been available to 100+ out of a total of 700,000 persons with disabilities. Following a successful pilot and advocacy by the CIL, it was listed as a service option in the Social Protection Law (personal communication from Sanja Nikolin, 2012).
Russia	A network of services for children with disabilities and their families has been developed in every region of Russia. Though these services are based on the medical model of disability and focus on message and other medical or quasi-medical procedures, they are valued by the parents (Rogers, 2012, p.1).

4.2.2 ALLOCATING FINANCIAL, MATERIAL AND HUMAN RESOURCES

This study has identified three key areas requiring attention under this heading, namely: (a) insufficient legal and financial framework for community living, (b) inadequate financial planning, and (c) limited funding for new services.

INSUFFICIENT LEGAL AND FINANCIAL FRAMEWORK FOR COMMUNITY LIVING

Study respondents from **Armenia, Azerbaijan, Moldova, and Serbia** all reported problems arising from existing legal and financial frameworks for community living. In **Azerbaijan**, for example, the main problems are caused by the regulations that allocate funding on the basis of *bed occupancy* and make it almost impossible to fund community-based services (personal communication, 2012). A study respondent for **Moldova** highlighted the limited financial resources planned by the state for the development of community-based services, an underdeveloped mechanism on social contracting and the lack of financial motivation for potential funders as the key barrier legal and financial barriers to community living (personal communication, 2012). Serious concerns about the sustainability of existing mental health centers have been expressed by the EC in the **Republic of Macedonia** (EC, 2013c, p. 55). Limited progress has been reported in **Bosnia and Herzegovina**, where some steps have been taken to harmonize the social protection systems in the Cantons. However, funding is still based on status, as opposed to individual needs of people with disabilities (EC, 2013b, p. 18)

INADEQUATE FINANCIAL PLANNING

Though few study respondents were able to identify work undertaken by governments or others to provide cost-comparisons between institutional care and community-based services (**Azerbaijan, Armenia, and Albania** were exceptions), the importance of well-informed financial planning was highlighted by a UNICEF Armenia (2010) study that concluded:

> *The [relocation] of children into family care does not necessarily lead to the creation of an additional burden on the state budget. On the contrary, depending on the policy chosen, the*

> *savings can be quite tangible, even if the reform costs include the provision of jobs to excessive staff of the discharged residential institutions and additional social support and care services for children released from residential institutions and their families. (p. 7)*

LIMITED FUNDING FOR NEW SERVICES

Lack of resources is often cited by countries as one of the main reasons for not making progress on deinstitutionalization. However, it is not necessarily the lack of resources that creates the problem. Rather, in countries with institutions for people with disabilities, it is more likely to be that resources are tied up in maintaining institutional care. In **Belarus**, for example, there are 46 institutions for children. Two are run by the Social Welfare Ministry, three by the Health Ministry, one by the Justice Ministry, and the remaining 40 by the Ministry of Education. The fact that the Ministry of Education was mandated to administer the process of deinstitutionalization is seen as one of the main reasons for the lack of progress, due to its reluctance to shift the current institutional budgets to other ministries (personal communication, 2012).

Reluctance to reallocate the funding was also noted in **Kosovo**, where in 2009 an international NGO was invited by the Kosovo government to develop a plan for the closure of the Special Institute in Shtime. The NGO proposed moving residents to small group homes or private homes within the community. A feasibility study showed that the proposed models would not cost the Ministry of Labor and Social Welfare more, "since the funds allocated for operating the Special Institute in Shtime would be enough to pay for either of the two proposed scenarios." Neither of the two models was implemented by the government, however, because of the perception that costs would be higher (People in Need, 2012, p. 109).

Other challenges identified by this study include the lack of capacity by the local governments in **Albania** to raise funding (Ministry of Labor, Social Protection and Equal Opportunities, 2011) and the limited fiscal and administrative decentralization of social services, which act as a barrier to the provision community-based services (EC, 2012a, p. 46). This is compounded by the failure of the line ministries to consider the needs of people with disabilities in their programs and budgets (EC, 2013a, p. 44). A praiseworthy initiative was reported in **Russia**, where the government created the Foundation for the Support of Children in Difficult Life Situations. The Foundation provides co-financing to regional governments with the aim of advancing child welfare reforms (Rogers 2012a, p. 2).

4.2.3 DEVELOPING HUMAN CAPACITY (PILLAR 3)

The availability of appropriately trained staff is one of the key conditions for providing quality support services in the community and requires a focus on building and retaining a qualified workforce to deliver services in the community. Study respondents raised two broad areas of concern in the E&E region. These are (a) the lack of appropriately trained staff, low salaries, and staff turnover; and (b) underdeveloped training for professionals on social inclusion issues.

A significant consequence of these problems is that staff continue to base their work on a the outmoded medical model of disability in that they focus on individuals' medical conditions rather than considering the needs and aspirations of the person, and how the person could be supported to engage in community life. This can result in plans containing mainly medical and corrective measures or an emphasis on so-called special arrangements, such as referring children to special boarding schools or prescribing medication instead of support (Common European Guidelines, 2012). For example in **Russia**, although significant changes have resulted in children with disabilities being entitled to cash benefits and social and medical services, based on an individual rehabilitation program, these benefits and services are limited by: (a) specialists' lack of knowledge and understanding of what they can recommend for a child, (b) the limited range of services and interventions that can be funded, and (c) the heavy focus on *curative* or medical services (Rogers, 2012a). In the **Republic of Macedonia**, the classification of *special needs* is based on a medical model that is unable to differentiate between disabling conditions and social disadvantages. This can lead to children *without disabilities* from socially disadvantaged backgrounds being classified as *disabled* (Velichkovski and Chichevalieva 2010, p. 25).

In **Serbia**, the criteria for assessing a person's capacity to work under the Law on Professional Rehabilitation and Employment of Persons with Disabilities are based on the medical model of disability and underestimate the actual capacity of people with disabilities to work. As a result, people with intellection disabilities are offered "work therapy" or "rehabilitation centers" that provide occupational therapy, not actual work or employment (personal communication, 2012).

4.2.4 PERFORMANCE OUTCOMES AND MEASURES (PILLAR 4)

Effective monitoring and evaluation of services is necessary to ensure that community-based services are of good quality and are based on principles that focus on the rights and quality of life of the people receiving services. *Regrettably, monitoring and evaluation of services have received scant attention in the E&E region to date.* Little or no information was available on governments' progress developing performance outcomes and measures.

4.2.5 INCREASING AWARENESS AND PARTICIPATION (PILLAR 5)

Three main challenges have been identified in relation to Pillar 5, which is focused on supporting individuals and communities during the transition process and therefore relevant to all aspects of the deinstitutionalization strategy. They are: (a) negative public attitudes towards people with disabilities, (b) insufficient capacity of people to advocate for reforms, and (c) lack of evidence of beneficial outcomes.

NEGATIVE PUBLIC ATTITUDES TOWARDS PEOPLE WITH DISABILITIES

In **Russia**, for example, it was reported that professionals working in social services "don't [know] modern approaches and in many cases think that…children [with disabilities] don't have any [prospects]." In addition, earlier research has shown that professionals working in health care and education often recommend to parents of children with disabilities to place their child in an institution (Rogers, 2010, p. 1).

INSUFFICIENT CAPACITY OF PEOPLE WITH DISABILITIES TO ADVOCATE FOR REFORMS

Research into reasons for institutionalization of children with disabilities in **Russia** revealed that parents with a lower level of education were unable to advocate for better services on behalf of their child and are more likely to accept advice from professionals about placing their child into institutional care, such as a special school (Rogers, 2010). Similarly, in the **Republic of Macedonia**, lack of training for parents of children with disabilities is an obstacle to including children with disabilities and their families in the community (Velichkovski and Chichevalieva, 2010, p. 26).

LACK OF EVIDENCE OF BENEFICIAL OUTCOMES

The present study has identified examples of projects that demonstrate the positive outcomes of living in the community for persons with disabilities and their families. Unfortunately, governments tend to finance small, short-term projects and then discontinue funding when the project is over, even when the results were good. Some of these projects also depend on international donor funding, which does not make them sustainable.

4.3 THE ROLE OF DONORS IN THE TRANSITION TO COMMUNITY LIVING

International donors can play an important part in the deinstitutionalization process because the real or perceived lack of funding is such a major barrier. Donor funding can provide the essential financial means and technical support to initiate community-based services. In **Serbia**, for example, "International funders have been playing a very significant role since many of the projects supporting process of transformation are funded by the EU" (personal communication, 2012). This is not always the case, however, and there appear to be three donor-related problems, namely (a) unwillingness of donors to engage in deinstitutionalization projects, (b) uncoordinated approaches that fail to correspond with local needs, and (c) continued finance for projects that reinforce institutionalization.

UNWILLINGNESS OF DONORS TO ENGAGE IN DEINSTITUTIONALIZATION PROJECTS

Concerns about the international funders being unwilling to engage in the process of deinstitutionalization have been expressed by respondents in **Azerbaijan, Moldova, and Belarus**, although in **Azerbaijan and Moldova** it was noted that the Open Society Foundations were an exception to this concern (personal communication, 2012).[13]

UNCOORDINATED APPROACHES THAT FAIL TO CORRESPOND WITH LOCAL NEEDS

In **Moldova**, the majority of community-based services have been developed by NGOs in partnership with local authorities in an opportunistic manner depending on the availability of financial resources offered by international donors. That is why services are not consistently and systematically available and do not correspond with the real needs of people with disabilities in different *rayons* (personal communication, 2012).

Similarly, analyzing the impact of international donors in **Kosovo**, a Disability Rights International (DRI, 2010) study concluded:

> *[The presence of a number of international actors] failed to produce closure of a single institutional facility for long term residence of persons with disabilities, as well as comprehensive development of community alternatives.... Over the years, through these uncoordinated efforts, several projects were implemented resulting in development of only isolated solutions to community care (at best) or renovating the institution itself (at worst) (p. 1).*

FINANCING PROJECTS THAT REINFORCE INSTITUTIONALIZATION

DRI (2010) cited the failings of international donors to promote community living in examples from **Kosovo and Serbia**, among others. DRI concluded "the international community fails to effectively influence national authorities in the process of transition from institutional to community-based care, allowing preservation of institutional system and replication of its culture into new services." DRI pointed out that while day centers developed in **Serbia** provide a useful service to people with disabilities and their families, they are "being supported and promoted in the form [that] directly violates children's right to education." The day centers offer a full-day stay and the children attending "are not only excluded from any meaningful educational programs, but are again congregated based on the type of their disability and prevented from interacting with non-disabled peers." Some of the day centers are even located on the premises of residential institutions.

The link between refurbishment of institutions and delays in carrying through deinstitutionalization has policy implications for international donors. USAID (2009b) found that humanitarian attempts to improve the conditions in institutions can backfire. "The refurbishment of institutions to a level that is above the living conditions of the general population will work against the goal of deinstitutionalization and will increase the perception that the state can provide better care than the family does" (p. 33). Such refurbishment inhibits family reunification: children find it difficult to re-adapt to poor physical family living conditions and the community-at-large comes to resent the perceived preferential treatment.

In its report on EU funding and the right to community living, the Open Society Foundations (2012) considered that EU *structural funds* should only be used to renovate institutions in very limited circumstances: (a) where there is "a clearly identified and compelling case to take limited action (for

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[13] USAID and other donors have supported deinstitutionalization activities in the past, but funding for such programs has decreased.

example to prevent an urgent and life threatening risk to the residents)," and (b) their use "forms part of a wider strategic program to develop community living" (p. 75). A similar approach should be taken in relation to funding from other international donors.

4.4 CONCLUSION

While the information currently available is incomplete and much of the information presented in this study is from unofficial sources, the findings indicate that progress is extremely limited in most countries. The main reason for this lack of progress is that governments have yet to make serious commitments to deinstitutionalization for all people with disabilities. There is a clear need for concerted action to drive forward the transition from institutional care to community living. Recommendations on how USAID Missions might assist this work and help address the barriers to achieving community living reviewed above are presented in Chapter 5.

5. CONCLUSIONS AND RECOMMENDATIONS

Deinstitutionalization is a complex process that cannot be completed overnight. Shortcuts can result in relocating residents to inappropriate services or abandoning them with no services at all. This study highlights reasons for the slow progress towards positive reform and recommends activities that address these challenges. Several key barriers—(a) lack of political will to effect necessary reforms, (b) lack of community-based alternatives to institutionalization, and (c) stigma and discrimination against people with disabilities—are addressed by Recommendations 1, 5, and 10 respectively.

The recommendations that follow are for use by USAID Mission staff to encourage strategic planning and effective deinstitutionalization activities that: (a) address existing and potential barriers that impede the transition to community living, and (b) seize current opportunities to advocate for necessary changes. The recommendations are organized within the framework for analysis used throughout the study. While these activities are generally applicable across the entire region, representatives of NGOs participating in this study recognized the particular importance of some to their national needs. These connections are noted in footnotes below. Practical resources related to implementing these recommendations are listed in Annex 6.

The starting point for reform will vary. In some countries, the process may start with children with disabilities, in others with adults. Decisions about where and how to start should be made while working on a deinstitutionalization strategy, in consultation with all relevant stakeholders and based on an assessment of each country's circumstances. Given the complexity of the deinstitutionalization process and the lack of information to guide reform, the first two recommendations focus on the need for official action based on an in-depth analysis of the situation in each country.

RECOMMENDATION 1. Make the case for developing community-based alternatives to institutions (CEG1)

1. USAID Missions need to highlight the need for reform and persuade governments that urgent action is required to develop community-based services.[14]

2. Fund projects and provide technical assistance for the development of a more effective means of collecting data on disability, taking into account Article 31 of the CRPD which requires States to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the [CRPD]."

3. Make clear to potential grantees that services that reinforce social exclusion and segregation of people with disabilities, contrary to Article 19 of the CRPD, will not be supported. All available funding should go toward developing quality community-based alternatives to institutionalization and should accord with any existing deinstitutionalization strategy.

RECOMMENDATION 2. Assess the situation in each country (CEG2)

USAID Missions that wish to initiate new or develop existing deinstitutionalization projects should support an in-depth analysis of the countries in which they are working. A comprehensive, in-depth assessment of the situation in a country should cover: (a) the needs of children and adults with disabilities and how social care, health care, and educational systems respond to them; (b) the barriers to using mainstream services; (c) the situation of people with disabilities and the reasons for institutionalization; (d) an assessment of the resources currently available within the child protection, social care, health, and education systems, and information about existing community-based services.

1. Highlight the need for an in-depth, country-by-country analysis and where appropriate provide financial and technical assistance for such studies.

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[14] Respondents from Azerbaijan and Georgia highlighted this as being of particular relevance.

2. Provide funding for a range of activities, such as workshops and seminars on how to develop a vision for community living, to engage all individuals and organizations that have responsibility for or an interest in providing services for people with disabilities. The purpose of such activities is to help develop among all stakeholders, including relevant Ministries, such as those responsible for finance, a common understanding of what needs to be accomplished and a recognition of the importance of coordinated efforts to complete the agreed actions within agreed timescales.

RECOMMENDATION 3. Develop strategies and action plans (CEG3)

1. Help governments draft and implement deinstitutionalization strategies and action plans by providing technical assistance to their task forces and working groups. Involve all relevant government departments and organizations representing the interests of people with disabilities.

2. Fund capacity building activities that will enable local authorities to assess the needs in their local communities and assist local authorities in developing strategies and action plans.[15]

3. Coordinate deinstitutionalization projects with other international donors that share an interest in disabilities, social and health care reform, and link these projects with a country's existing deinstitutionalization strategy and action plan or strategy development work.[16]

4. Support study visits, training, and other activities that build local and regional actors' capacity to (a) implement deinstitutionalization programs and (b) support people with disabilities to live in the community.[17]

RECOMMENDATION 4. Establish the legal framework for community-based services (CEG4)

1. Support government reviews of legislation and policy, including legal capacity legislation, in accordance with the CRPD. The review process should include: (a) detailed analysis and recommendations on law and policy, including a timeframe for implementation and a monitoring mechanism, and (b) review of administrative rules on providing and financing services to establish whether they create obstacles to deinstitutionalization.[18]

2. Fund training on the CRPD and the Convention on the Rights of the Child (CRC) for all relevant stakeholders, including government departments and agencies, social and health care professionals, other service providers, trade unions, people with disabilities and their families. Include organizations representing people with disabilities in preparation and delivery.[19]

RECOMMENDATION 5. Develop a range of services in the community (CEG5)

1. Fund support for implementing pilot projects of innovative services such as early intervention and other preventive services, foster care, family support services, personal assistance, supported living, supported employment, inclusive education, and personal budgets. These innovative services should be cost effective, based on European and international good practice, and should be part of an overall deinstitutionalization strategy. In developing such services, consideration should be given to sustainability of funding and to how they relate to the five pillars.[20]

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[15] Study respondents noted particular relevance to the Republic of Macedonia and Serbia.

[16] A study respondent noted particular relevance to Moldova.

[17] Study respondents noted particular relevance to Georgia and Moldova.

[18] A study respondent noted particular relevance to Georgia.

[19] Study respondents noted particular relevance to countries in the region that have ratified the CRPD and the CRC.

[20] Study respondents noted particular relevance to Albania, Armenia, Azerbaijan, Georgia, Kosovo, and the Russian Federation.

2. Support ongoing reforms by organizing study visits and exchanges for policy makers, service providers, professionals, and organizations of people with disabilities to countries demonstrating good deinstitutionalization practices and trainings involving European and international experts. In countries where nongovernmental organizations are providing community-based services and advocating for community living, funding could be made available to organizations willing to develop training programs and study visits on a national and international basis. This will address the issue of lack of knowledge on how to develop community-based services.[21]

3. Fund deinstitutionalization initiatives that make mainstream services available and accessible to people with disabilities. Ensure that people with higher support needs are served from the beginning so that experience and know-how can immediately benefit people with lower support needs. International funding should be used to support parts of the deinstitutionalization process that cannot be covered by the government, such as development of mainstream social housing to support new services in the community.[22]

RECOMMENDATION 6. Allocate financial, material, and human resources (CEG6)

1. Fund national studies comparing the cost of institutional care with community-based services to ensure that government planning for the transition to community-based services anticipates the initial investments (hump costs) and transition funding needed while two systems run in parallel.

2. Provide technical assistance to help governments develop targeted funding strategies for all stages of deinstitutionalization and development of community-based services.[23]

RECOMMENDATION 7. Develop individual plans (CEG7)

Provide technical assistance to help governments develop effective case management and gatekeeping mechanisms to ensure that people receive services appropriate to their needs.[24]

RECOMMENDATION 8. Develop the workforce for deinstitutionalization (CEG10)

Fund development of training modules and delivery of initial and ongoing training of staff to work in community-based services. Training should focus on showing that the move towards community-based services must be accompanied by a shift towards a social model of disability, which helps professionals see that the main disabling factors are physical and attitudinal barriers in the environment that can and must be removed so individuals can fully participate in society.[25]

RECOMMENDATION 9. Define, monitor, and evaluate the quality of services (CEG9)

1. Support capacity building to help policy makers at the ministerial level develop effective mechanisms to ensure meaningful participation of civil society actors (non-governmental organizations with experience delivering community-based services, organizations of people with disabilities, individuals with disabilities and their families) in developing monitoring and evaluation standards, and in implementing, monitoring and evaluating services.

2. Fund assessment and demonstrate positive outcomes for persons with disabilities involved the pilot projects suggested in Recommendation 5-1 and 5-2 above.

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[21] Study respondents noted particular relevance to Belarus.

[22] Study respondents noted particular relevance to Georgia, Moldova, the Russian Federation, and Serbia.

[23] Study respondents noted particular relevance to Moldova.

[24] Study respondents noted particular relevance to the Russian Federation.

[25] Study respondents noted particular relevance to Azerbaijan, Georgia, and the Republic of Macedonia.

RECOMMENDATION 10. Support individuals and communities during transition (CEG8)

1. Provide technical and financial support so that organizations representing people with disabilities or advocating for community living can take part in drafting and implementing deinstitutionalization strategies and action plans, and in monitoring and evaluation activities.[26]

2. Provide funding to enhance capacity building (e.g., training in advocacy and policy development) so that organizations representing children and people with disabilities can participate meaningfully in reviews of policy, legislation, and other matters concerning the deinstitutionalization process.

3. Support public awareness campaigns on the right of people with disabilities to live in the community.

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[26] Study respondents noted particular relevance to Georgia.

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ANNEXES

ANNEX 1: REGIONAL CLASSIFICATIONS BY DONOR

Council of Europe Member States (47 countries)[a]	**CEE/CIS** (22 countries—UNICEF)[b]	**Europe & Eurasia** (13 countries—USAID)[c]
Albania	Albania	Albania
Andorra		
Armenia	Armenia	Armenia
Austria		
Azerbaijan	Azerbaijan	Azerbaijan
	Belarus	Belarus
Belgium		
Bosnia and Herzegovina	Bosnia and Herzegovina	Bosnia and Herzegovina
Bulgaria	Bulgaria	
Croatia	Croatia	
Cyprus		Cyprus
Czech Republic		
Denmark		
Estonia		
Finland		
France		
Georgia	Georgia	Georgia
Germany		
Greece		
Hungary		
Iceland		
Ireland		
Italy		
	Kazakhstan	
	Kosovo	Kosovo
	Kyrgyzstan	
Latvia		
Liechtenstein		
Lithuania		
Luxembourg		
Former Yugoslav Republic of Macedonia	Former Yugoslav Republic of Macedonia	Former Yugoslav Republic of Macedonia
Malta		
Republic of Moldova	Republic of Moldova	Republic of Moldova
Monaco		
Montenegro	Montenegro	
Netherlands		
Norway		
Poland		
Portugal		
Romania	Romania	
Russian Federation	Russian Federation	Russian Federation

Council of Europe Member States (47 countries)[a]	**CEE/CIS** (22 countries—UNICEF)[b]	**Europe & Eurasia** (13 countries—USAID)[c]
San Marino		
Serbia	Serbia	Serbia
Slovak Republic		
Slovenia		
Spain		
Sweden		
Switzerland		
	Tajikistan	
Turkey	Turkey	
	Turkmenistan	
Ukraine	Ukraine	Ukraine
United Kingdom		
	Uzbekistan	

Notes:

a. Retrieved from http://www.coe.int/aboutcoe/index.asp?page=47pays1europe

b. Retrieved from http://www.unicef.org/ceecis/region2.html

c. Retrieved from http://www.usaid.gov/where-we-work/europe-and-eurasia

ANNEX 2: POINTS OF DISCUSSION WITH REPRESENTATIVES OF NONGOVERNMENTAL ORGANIZATIONS

What is the purpose of the study?

The study was commissioned on behalf of the US Agency for International Development (USAID) in August 2012. Its objective is to provide background information and concrete suggestions for USAID Missions in Europe and Eurasia[28] that wish to add a specific focus on people with disabilities to their child welfare or deinstitutionalization programs,[29] or to design new programmes that provide community-based services to children and/or adults with disabilities.

What is the purpose of the interviews?

The purpose of the interview is to get a better picture of the situation of children and adults with disabilities in institutional care and the availability (if any) of community-based services in each of the relevant countries. The information obtained in the interview will be used to formulate conclusions about the situation in the region and to make recommendations to USAID missions on how they can facilitate the development of community-based alternatives to institutional care for children and adults with disabilities in the region.

There are several lines of inquiry based on the outline of the study. We would be very grateful if you could address questions you are able to comment on, giving as much information as you think relevant and wherever possible, providing sources of information, such as reports, academic articles, newspaper or online articles etc. *Please do not feel you have to answer all the questions.*

1. OVERVIEW OF THE CURRENT SITUATION OF CHILDREN AND ADULTS WITH DISABILITIES IN THE REGION

NUMBER OF PEOPLE WITH DISABILITIES IN INSTITUTIONS

1.1 What kind of information does your government keep about the people with disabilities generally, such as the percentage of people with disabilities as part of the total population? Is this information disaggregated by gender, age, type of impairment, etc.?

1.2 How many children and adults with disabilities are living in institutional care in your country? (Please state if such information is not available.)

1.3 What kind of information does your government keep about the residents in institutions – is this information disaggregated by gender, age, type of impairment, length of stay etc.? (If such information is not available, please let us know what, if any, information your government makes available about people with disabilities in institutions.)

1.4 Is there any evidence as to whether male (or female) children are more likely to be institutionalised? (If yes, please provide details, such as references to reports, statistics or any general observations you think relevant.)

1.5 Is there any evidence that people with certain impairments (such as intellectual disabilities, autism, physical disabilities etc.) are more likely to be institutionalised than others? (If yes, please provide details, such as references to reports, statistics or any general observations you think relevant.)

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[28] The study will cover Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Georgia, Kosovo, Republic of Macedonia, Moldova, Montenegro, Russian Federation, Serbia, and Ukraine.

[29] The term *deinstitutionalization programs* is used to describe coordinated activities that seek to ensure the closure of long-stay institutions by developing community-based services and support for people with disabilities as alternatives to institutional care.

SITUATION OF PEOPLE IN INSTITUTIONS

1.6 Have there been any reports in your country concerning the situation of people in institutions? (If, yes please provide details, such as web-links to any such reports any observations you would like to make about these reports.)

1.7 Have there been any reports or cases in your country illustrating the effects of institutionalisation on residents (such as cases of abuse, deaths etc.)? (If, yes please provide details, such as web-links to any such reports and any observations you would like to make about these reports.)

1.8 Are children/adults with disabilities likely to leave institutional care or do the majority remain in institutional care for life?

1.9 At what point in their lives, are people most likely to enter institutional care – for example, as children, when turning 18, as adults, or in old age?

1.10 What are the main reasons for a child or adult with disabilities being placed into institutional care? (For example, is this due to the lack of services and support to enable the person to live in their own home, or are there other/additional reasons for the placement in an institution?)

AVAILABILITY OF COMMUNITY-BASED SERVICES

1.11 What community support services are available? (These might include home support, personal assistance, early intervention, education, supported employment, personal budgets, peer counseling, community living, respite care and other family support services, rehabilitation, medication and psychotherapy.)

1.12 Is suitable accommodation available as an alternative to institutional care? For example, can people who are now living in institutions move to the community?

1.13 Is there a sufficient number of appropriately trained staff to work in community-based services (such as carers, social workers, clinical psychologists, psychiatrists, occupation therapists, and speech therapists)? If no, what, if any, plans are there to increase the number of qualified staff?

1.14 What are the barriers to the availability of services (for example, a lack of funding from government or elsewhere for the development of community based services)?

1.15 Are mainstream services, such as health, transport, education, childcare, sport accessible to people with disabilities (such as through adaptations and provision of appropriate support)? (If not, please provide any observations on the problems that people with disabilities have in making use of mainstream services you think may be of relevance to this study)

LEGAL AND POLICY FRAMEWORK

1.16 Are there any laws and policies that highlight the importance of providing support to people with disabilities to enable them to live in the community? (If yes, please provide details.)

1.17 Are there any laws and policies that mandate and set out a process for the creation and oversight of a range of community-based services? (If yes, please provide details.)

1.18 Are there any specific laws and policies that act as a barrier to the development or provision of community- based services? (For example, restrictions on NGOs providing community based services. If yes, please provide details.)

1.19 Are there laws that restrict or remove adults' right to make their own decisions about where and with whom they live (i.e., guardianship)?

OTHER BACKGROUND INFORMATION

1.20 Are there any other factors contributing to institutionalisation of people with disabilities which you feel should be highlighted? (If yes, please provide details.)

2. THE RIGHT TO LIVE IN THE COMMUNITY

INTERNATIONAL HUMAN RIGHTS FRAMEWORK

2.1 In countries that have ratified the UN Convention on the Rights of Persons with Disabilities (Armenia, Azerbaijan, Bosnia and Herzegovina, Republic of Macedonia, Moldova, Montenegro, Serbia and Ukraine), has a review of national legislation and policies for compliance with the UN CRPD been initiated?

2.2 If yes, does the review address key areas of concern, such as the use of guardianship and any existing legislative/policy barriers to the development of community-based services? (Please provide any additional comments on the review that you think might be relevant to this study.)

BETTER USE OF RESOURCES

2.3 Have there been any studies comparing the cost of institutional care and community-based services in your country? (If yes, please provide further details and any observations you would like to make about these studies.)

3. TRANSITION FROM INSTITUTIONAL TO COMMUNITY-BASED CARE

NATIONAL STRATEGY FOR DEINSTITUTIONALIZATION

3.1 Has the Government made an explicit commitment to transforming the system from institutional services to community-based services? If so, how? (For example this might be through a national strategy for deinstitutionalisation.)

3.2 If there is a strategy, does it include a clear timetable, targets and benchmarks for measuring progress and budget and resources allocation? (Please provide any additional observations you think relevant.)

3.3 Is the strategy supported by all relevant government bodies, e.g., Ministry of Health, Ministry of Social Welfare, Ministry of Education, Ministry of Finance etc? If so, does the strategy explain each department's responsibilities, financial contribution and how they will coordinate among themselves?

3.4 Are there any action plans for the closure of existing institutions?

3.5 Where there is a national strategy, or other plans, concerning the development of community based services as alternatives to institutional care, were organisations of/for people with disabilities actively involved in their preparation?

BARRIERS TO THE PROCESS OF DEINSTITUTIONALIZATION

3.6 What do you consider to be the main barriers/challenges to the transition from institutional to community-based care in your country? Please feel free to highlight as many issues as you think relevant, such as problems:

- at the government level (such as insufficient legal and financial framework, lack of commitment from the relevant Ministries)
- at the service delivery level (such as lack of knowledge in how to develop services, insufficient qualified staff),
- with resources (lack of funding, resources being tied up in institutional care and/or
- with public perception (negative attitudes towards people with disabilities).

3.7 What action do you think could be taken to address these barriers? What opportunities might be available to help to address such barriers?

THE ROLE OF INTERNATIONAL FUNDERS

3.8 How would you evaluate the role that international funding agencies (and the European Union) have played in the process of de-institutionalisation?

3.9 What recommendations would you give to international funding agencies to help them improve their strategies for funding deinstitutionalisation programmes and other programmes that seek to develop community based services for people with disabilities?

GOOD PRACTICE

3.10 Are there any deinstitutionalisation projects or community-based services in your country that you would single out as examples of good practice? If yes, please describe the service briefly. If possible it would be helpful to have information on who provides the service, who the service is for, and how it is financed. If it would be easier to put us in touch with the organisation that provides this service, we would be grateful if you could provide the name and email address of the organisation's representative.

ANNEX 3: RESPONDENTS TO THIS STUDY

Name	Position, Organization	Country
Armen Alaverdyan	Director, UNISON NGO for Support of People with Special Needs	Armenia
Ramiz Behbudov	Director, Social Services Initiative	Azerbaijan
Vigan Behluli	Consultant, Kosovo Mental Disability Rights International	Kosovo
Enira Bronitskaya	Director, Office for the Rights of People with Disabilities	Belarus
Dragana Ćirić Milovanović	Director, Mental Disability Rights Initiative – Serbia	Serbia
Sergey Drozdovsky	Coordinator, Office for the Rights of People with Disabilities	Belarus
Floriana Hima	Project Officer (Child, Youth and Family Protection Program), UNICEF	Albania
Nino Makshashvili	Director, Global Initiative for Psychiatry (GIP) Georgia	Georgia
Biljana Lubarovska	Project Officer (Child Protection), UNICEF Skopje Office	Republic of Macedonia
Ludmila Malcoci	Director, Keystone Human Services International Moldova Association	Republic of Moldova
Jo Rogers	Partnership for Every Child	Russian Federation
Denise Roza	Director, Perspektiva	Russian Federation
Jean Claude Legrand	Senior Regional Advisor Child Protection, UNICEF Regional Office CEE/CIS	—

ANNEX 4: NUMBER OF CHILDREN & ADULTS LIVING IN INSTITUTIONAL AND RESIDENTIAL CARE

PROBLEMATIC DATA ON THE PREVALENCE OF DISABILITY

Deinstitutionalisation and community living – outcomes and costs: report of a European Study ("the DECLOC report") noted that, according to Article 31 of the CRPD, State Parties to the Convention are required to collect "appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" and that information collected "shall be disaggregated as appropriate" and used to "identify and address the barriers faced by persons with disabilities in exercising their rights" (Mansell et al., 2007, p. 94).[30]

The DECLOC report found, however, that in many countries, even when data existed at a regional or local level, these data were not necessarily collected at a national level. Where data were available, "there was…little evidence of standardized definitions and classification, so that it was not possible to be confident that information from different sources from each country, let alone between different countries, was completely comparable (p.12)." In the Republic of Macedonia, for example, although there has been progress in data collection supported by UNICEF and administered by the Institute for Social Activities, Velichkovski and Chichevalieva (2010) noted that the statistics on children with disabilities included only children who use services or whose parents are members of nongovernmental organizations: "People with disabilities—especially children—who are kept at home are not included in any statistics" (p. 17).

Insufficient recording of data makes it impossible to confidently describe the extent of the deinstitutionalization challenge, and, conversely, improving data collection is essential to supporting the transition to community-based services. *The Prevalence of Disability in Europe and Eurasia* (USAID, 2009c) concluded:

> *The challenges in collecting the data and the questions about the validity of the data (given the differences in the definitions and models used) indicate that more rigorous data collection and reporting practices would improve the knowledge about disability in the region and increase the likelihood that effective services can be delivered. (p. 33)*

PROBLEMATIC DATA ON THE NUMBER OF CHILDREN AND ADULTS WITH DISABILITIES IN INSTITUTIONAL CARE

Although more data are available on the number of children in institutions than for adults, these figures are not necessarily more reliable: they are based on estimates relating to different geographical areas.

- A Eurochild national survey estimated that there were approximately one million children in state/public care in the 30 European countries (all EU Member States, including the four nations of the UK, and Moldova).
- Mulheir (2012) estimated that "it is likely that between 600,000 and 1,000,000 children are separated from their families and live in large residential institutions that cannot meet their needs" in the 50+ countries included in the United Nations definition of Europe (including Albania, Belarus, Bosnia and Herzegovina, Republic of Macedonia, Moldova, Montenegro, Russian Federation, Serbia, and Ukraine—nine of the 13 countries considered by this report). Furthermore, notwithstanding the shortage of accurate statistics "existing research suggests that children with disabilities are significantly over-represented in these institutions" (p. 117).

Eurochild (2010) noted that one reason for the lack of comparable data is the use of differing definitions of *residential care* and *alternative care* noted in Chapter 2 of this report. UNICEF's database, TransMonEE

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[30] Mansell et al gathered information on people placed in institutional care in the 27 member states of the European Union and Turkey.

(Transformative Monitoring for Enhanced Equity)[31] uses the term residential care to include children in infant homes, in orphanages, in boarding homes and schools for children without parental care or poor children, disabled children in boarding schools and homes, family-type homes, SOS villages, etc. Children in punitive institutions are normally excluded.

Table A1 below indicates the numbers of children and adults in institutional care in the region by country, along with the source of the information. Additional information is provided in the table notes.

TABLE A1.

Children and adults with disabilities in institutional care in Europe and Eurasia

Country	Children	Adults	All Ages	Source (Date)
Albania	< 357 children	< 783 adults		Ministry of Social Affairs and Equal Opportunities (personal communication, 2012) [a]
Armenia	4,795 children [b]	n/a		UNICEF (2010)
Azerbaijan	2,804 children (2011) [c]	816 adults (2011) [d] 732 adults (2012)		State Statistics Committee of Azerbaijan (personal communication, 2012) [e]
Belarus	n/a [f]		approx. 15,000 [g]	(personal communication, 2012)
Bosnia and Herzegovina	78 children (FB&H, '11) 50 children (RS, '11)	1,848 adults (FB&H, '11) 311 adults (RS, '11)	1,926 (F=848, M=1,078) (FB&H, '11) 361 (F=150, M=211) (RS, '11)	People in Need (2012)
Georgia	450 children	n/a [h]		Ministry of Labour, Health and Social Care (2012)
Kosovo	< 20 children	56 PWID [i] + 9 [j] 58 PWMHP [k]		People in Need (2012) and (personal communication, 2012) [l]
Republic of Macedonia	182 children	325 adults		National Strategy for Deinstitutionalization (2007)
Republic of Moldova	588 children [m]		2,100 people with disabilities, including 1,700 PWID [n]	Ministry of Education and the Ministry of Labor, Social Protection and Family (personal communication, 2012)
Montenegro	338 children (F=133, M=205) (2010) [o]	377 adults (2010) [p] 118 PWID (2012)		children (official statistics, 2010) adults (The Public Institute "Komanski Most" annual report, 2012)
Russian Federation	164,700 children (2009) [q]	n/a	124,600 PWD 164,752 PWMHP (2005) [r]	children (official statistics, 2009) PWD & PWMHP (official statistics, 2005)

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[31] Available at: www.transmonee.org/index.html

Country	Children	Adults	All Ages	Source (Date)
Serbia	439 children [s]	1,658 PWID 253 PWD 2,386 PWMHP [t]		People in Need (2012) and personal communication, 2012
Ukraine	>70,000 children [u]			Ministry of Social Policy and Labour (2009)
Total	**319,663**	**9,612**	**308,739**	

Abbreviations:
< = less than; > = greater than; FB&H = Federation of Bosnia and Herzegovina; RS = Republika Srpska; PWD = people with disabilities; PWID = people with intellectual disabilities; PWMHP = people with mental health problems

Table A1 notes:

a. *Albania*. These figures include 177 children under 16 years old in public institutions and 180 in private institutions; 239 young people and adults above 16 years old in public institutions and 544 in private institutions, which include day care centers for people with disabilities.

b. *Armenia*. This total includes 871 children in state-run orphanages, 212 children in orphanages run by charitable organizations, 754 children in "night care centers," and 2,893 children in "special boarding schools." State orphanages include two baby homes, one of which is a specialized institution for children aged 0–6 with disabilities, one orphanage for older children with disabilities, two orphanages for children ages 0–18 and older, and three orphanages for school-age children aged 6–18. Night care centers were created after the restructuring of boarding schools and accommodate children who were returned to their biological families, but whose families lack resources to keep them at home. These centers cater to school-aged children, who reportedly spend five nights a week in the center and spend weekends and vacations with their families. Special boarding schools accommodate children with disabilities and are run either by the Ministry of Education and Science (1,442 children in 12 schools in 2009) or by local authorities (1,222 children in 13 schools in 2009). Those run by the Ministry include two schools for children with anti-social behavior, one school for children with hearing impairments, one school for children with visual impairments, and one school for children with speech impairments. Local special boarding schools are not impairment specific, except for children with visual impairments; they are for children who have difficulties with learning. According to UNICEF, schools run by local authorities are more likely to accommodate children whose main problem is poverty and social neglect and are sometimes misleadingly described as "boarding schools of general type."

c. *Azerbaijan*. This total includes 267 children in two institutions for children with "severe mental/intellectual disabilities" and 2,537 children in 12 institutions for children with other types of sensory or intellectual disabilities. The two institutions for children with severe disabilities are run by the Ministry of Labour and Social Policy, as these children are considered "non-educable." Their maximum capacity was decreased from 600 in 2010 to 300 in 2012. The rest of the children's institutions are run by the Ministry of Education.

d. *Azerbaijan*. Adults with disabilities are accommodated in seven institutions.

e. *Azerbaijan*. Reportedly, the actual number of children in institutions is about 40–60% smaller than officially reported because institutions are paid per child and directors of institutions continue to register "ghost" children in order to receive a full budget allocation.

f. *Belarus*. According to the available information, there are ten institutions for children with disabilities, but the number of children in these institutions is not known.

g. *Belarus*. There are 76 residential institutions (*internats*) for older people and people with disabilities run by local authorities and one institution run by the state. These include 22 institutions for people with disabilities and older people, 45 institutions for people with psycho-social disabilities, and ten for children with disabilities. More than 17,700 people live in these institutions, of whom approximately 15,000 (85%) are people with disabilities.

h. *Georgia*. While accurate data is not available, the number of psychiatric and other institutions for adults with disabilities is reportedly "very high." In addition, it has been suggested that the real numbers exceed any officially reported data by at least three times (personal communication, 2012). In a monitoring report on institutions for persons with disabilities published by the Public Defender's of Georgia (2010), two institutions accommodating adults with disabilities (Dzevri Boarding House for Persons with Disabilities and Dusheti House) are listed, as well as two institutions for older persons with disabilities (Tbilisi Boarding House for Elderly Persons and Kutaisi Boarding House for Elderly Persons). However, no data were provided about the number of people in these institutions.

i. *Kosovo*. This figure refers to the residents of the Special Institute in Shtime who are placed in facilities for people with intellectual disabilities and delays in mental development run by the Ministry of Social Labour and Welfare. There are separate facilities for people with mental health problems. See note 11 below. Since 2006–2007, there has been a rapid decrease in the number of residents: Of the 70 residents who left the institution, most (38) were transferred to community-based homes, nine were placed in other institutions ("homes for the elderly"), and 22 died. Just one resident returned to his/her biological family.

j. *Kosovo*. This figure refers to people with intellectual disabilities in homes for the elderly. There are currently three institutions housing older people in Kosovo, with a total of 110 residents. It is possible that homes for the elderly accommodate more than nine people with intellectual disabilities, but conclusive data are not available.

k. *Kosovo*. This figure refers to the residents of the Centre for Integration and Rehabilitation of Chronically Ill Patients in Shtime—part of the Special Institute in Shtime—that provides services to people with psychiatric diagnoses.

l. *Kosovo*. There were 191 people with disabilities in institutional care under the category "institution for people with disabilities and psychiatric institutions" recorded by the census in 2011. Discrepancy between the data presented in this table and those from the census may be due to the fact that people with psycho-social disabilities are being placed in the ten-bed psychiatric wards of the five regional hospitals. Psychiatric wards are not commonly considered *institutional care* because they provide short-term, acute care for people with psycho-social disabilities going through crises.

m. *Moldova*. This figure refers to children placed in seven special educational institutions for children with disabilities run the by Ministry of Education, all of which provide residential care. There are also five residential centers for children, including children with disabilities, run by the Ministry of Health. There is no information, however, about the actual number of children in the Ministry of Health institutions.

n. *Moldova*. According to the Annual Social Report 2011, 2,100 children and adults with disabilities are housed in nine institutions run by the Ministry of Labor, Social Protection and Family. The vast majority of these residents (1,700) have intellectual disabilities. There are no official data about people in institutions run by either the Ministry of Health or local authorities.

o. *Montenegro*. This figure refers to four social care institutions that provide residential care, nursing care, health care, education, and vocational therapy for children and young people with intellectual and physical disabilities. It is not clear whether all four institutions are long-term residential care institutions and whether they also include special schools.

p. *Montenegro*. In addition to adults with disabilities, this figure includes older people, older people with chronic and mental health illnesses, and those placed in one of the four social care institutions for social reasons. Of this total, 118 persons with disabilities (110 adults and eight children) live in the Komanski Most institution, a long-term residential facility only for people with intellectual disabilities.

q. *Russian Federation*. This figure includes 22,300 children with disabilities in children's *internat* homes under the Ministry of Labor and Social Protection, and 142,400 children in children's *internat* schools for children with developmental delays, under the Ministry of Education. The word *internat* (Russian for *boarding*) indicates that these are residential institutions.

r. *Russian Federation*. The 2007 Guardianship Report by the Mental Disability Advocacy Center provided an overview of nationwide data on social care and mental health institutions. At mid-decade, there were 442 social care institutions (residential "psycho-neurological institutions") in the country with a total of 124,600 beds and an average of 282 beds per institution. In addition, there were 277 psychiatric hospitals and 110 in-patient departments at out-patient psychiatric clinics with a total of 164,752 beds. These figures were taken from the State report of the Ministry of Health Care and Social Development of the Russian Federation and the Russian Academy of Medical Sciences (2005).

s. *Serbia*. This figure is dated September 2012 and should be considered an estimate. According to the Serbian Social Protection Institute (2011) there were 1,490 persons (32% children; 68% adults) in five institutions for children and youth with disabilities. People in Need (2012) listed six institutions for children and youth with intellectual disabilities and autism. This does not necessarily mean, however, that the residents' age and type of impairment corresponded to the institution's stated purpose. The Ombudsman's office also identified institutions for older people that were home to both younger and older persons with intellectual disabilities (p.157).

t. *Serbia*. These figures, published by the Serbian Social Protection Institute in 2011, refer to 1,658 persons in seven institutions for adults with intellectual disabilities, 253 persons in institutions for adults with primarily physical and sensory disabilities, and 2,386 persons in institutions for adults with psycho-social disabilities, so-called "homes for the mentally ill."

u. *Ukraine*. This figure (Bloemkolk, 2010) refers to children with disabilities living in 55 state-run *internat* (residential) institutions. These included 23 "level 3-4" institutions—for children considered severely disabled and "without prospects"—housing approximately 3,000 children, 4–18 years old. The rest of the institutions accommodated children with mild intellectual or physical disabilities considered as "having prospects" for some participation in society. It is worth noting that according to the TransMonee Database, among the 85,000 children in institutions, only 6,879 had disabilities.

TRANSMONEE DATA ON CHILDREN WITH DISABILITIES IN INSTITUTIONAL AND RESIDENTIAL CARE

NUMBER OF CHILDREN IN RESIDENTIAL CARE IN 2005 AND 2010

Table A2 below shows the estimated number of children with disabilities who were living in residential care[32] during 2005 and 2010 in the countries included in this study. These data are from UNICEF's TransMonEE database of all children in residential care and children with disabilities in residential care.

TABLE A2.

Children in residential care in Europe and Eurasia in 2005 and 2010

Country	All children 2005	All children 2010	Children with disabilities 2005	Children with disabilities 2010
Albania	800	900 [a]	315	371 [a]
Armenia	8,300	5,100	2,250	2,667
Azerbaijan	23,300	10,300	3,213	2,804
Belarus	25,500	17,300	10,179	6,275
Bosnia & Herzegovina	2,200	2,300	1,482	1,571
Georgia [b]	—	—	2,400 [c]	—
Kosovo [d]	—	—	—	—
Republic of Macedonia	900	700	552	390
Moldova	12,100	7,100	5316	3,655
Montenegro	500 [e]	500	342 [e]	338
Russian Federation	372,800	305,700	156,479	139,402
Serbia	5,100 [f]	3,100	3,296 [f]	1,543
Ukraine	92,600	85,000	7,475	6,879
Total	**538,500**	**437,100**	**187,261**	**165,524**

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[32] This term *residential care* refers to care provided outside an individual's home and can include both traditional long-stay institutions and residential care settings among the community-based services provided to meet the needs of children with disabilities.

Notes:

a. The figure is from 2009.

b. The data collected from Georgia are incomplete (not all institutions are covered)

c. This figure is an UNICEF-IRC estimate.

d. Data is not collected for Kosovo

e. Data from Montenegro are collected every two years. The figure is from 2004.

f. Data from Serbia are collected every two years. The figure is from 2004.

NUMBER AND RATE OF CHILDREN WITH DISABILITIES IN RESIDENTIAL CARE IN 2000, 2005, AND 2007

Table A3 below is derived from UNICEF (2010) Table 8.1 "Children with disabilities in residential care in 2000, 2005 and 2007." The rows marked in orange indicate the countries in which the number or rate increased between 2000 and 2007. In Albania, Bosnia and Herzegovina, Georgia, and Serbia, the figures show an increase in both numbers and rate. Table C above shows that this increase in numbers continued in 2010 for Albania and Bosnia and Herzegovina. In Serbia, however, the number of children with disabilities in residential care had decreased significantly by 2010—from 3,612 in 2007 (Table D) to 1,543 in 2010 (Table C). In Azerbaijan, Moldova, and Ukraine, even though the number of children in residential care decreased, the rate of children in residential care per 100,000 children in the general population increased. Kosovo was not included in the survey.

TABLE A3.

Number and rate of children with disabilities in residential care in Europe and Eurasia

Country	Number of children with disabilities 2000	Number of children with disabilities 2005	Number of children with disabilities 2007	Rate per 100,000 children (0–17 yrs) 2000	Rate per 100,000 children (0–17 yrs) 2005	Rate per 100,000 children (0–17 yrs) 2007
Albania	288	315	316	26	32	33
Armenia	4,875	2,250	1,707	442	263	213
Azerbaijan	2,979	3,213	4,290	102	122	168
Belarus	13,880	10,179	8,451	595	526	465
Bosnia and Herzegovina	1,238	1,482	1,511	132	165	173
Georgia	2,245	2,400	2,824	196	233	288
Republic of Macedonia	649	552	502	119	112	106
Moldova	4,788	5,316	4,674	457	618	574
Montenegro	390	342	366	227	217	241
Serbia	3,362	3,296	3,612	220	226	256
Russian Federation	183,976	156,479	141,848	549	560	537
Ukraine	7,977	7,475	7,158	74	85	86
Total	**226,647**	**193,299**	**177,259**			

INSTITUTIONALIZATION OF YOUNG CHILDREN, 0–3 YEARS OLD

Table A4 below is derived from UNICEF (2010) Table 7.1 "Young children (0–3 years old) in residential care in 2000, 2005 and 2007, at the end of the year." The rows marked in orange indicate the countries in which the numbers or rate increased between 2000 and 2007. Figures were not available for Montenegro or Serbia; Kosovo was not included in the survey.

TABLE A4.

Number and rate of young children 0–3 years old in institutions in Europe and Eurasia

Country	Numbers of young children in institutions 2000	Numbers of young children in institutions 2005	Numbers of young children in institutions 2007	Rate per 100,000 children (0–3 years) 2000	Rate per 100,000 children (0–3 years) 2005	Rate per 100,000 children (0–3 years) 2007
Albania	168	124	134	78	65	75
Armenia	80	74	80	32	34	37
Azerbaijan	197	156	105	42	32	18
Belarus	1,300	1,250	1,083	356	353	287
Bosnia & Herzegovina	328	330	207	180	216	133
Georgia	187	224	222	96	121	119
Republic of Macedonia	70	99	106	68	108	118
Moldova	355	361	361	223	247	241
Montenegro	—	—	—	—	—	—
Serbia	—	—	—	—	—	—
Russian Federation	19,345	20,621	18,480	383	358	309
Ukraine	4,969	5,200	4,398	308	318	249
Total	**26,999**	**28,439**	**25,176**			

ANNEX 5: HUMAN RIGHTS STANDARDS

The *UN Convention on the Rights of Persons with Disabilities* (CRPD) and its *Optional Protocol* (CRPD OP), which came into force in 2008, was the first human rights treaty to make the right to community living explicit. This right has strong links to the fundamental human rights principle of autonomy and its development can be traced to earlier human rights standards:

- *European Convention on Human Rights* (ECHR, 1953) includes the right to liberty (Article 5) and the right to private and family life (Article 8). An individuals' freedom to exercise choice and control is a core element of both of these rights. In Pretty v United Kingdom (2002), the European Court of Human Rights stated: "the notion of personal autonomy is an important principle underlying the interpretation of [these] guarantees" (p. 33).
- *Revised European Social Charter* (ESC, 1961; revised 1996) includes rights promoting community living for children (Article 16) and older people (Article 23), and rights for people with disabilities (Article 15). Article 15 requires States to act to promote "effective exercise of the right to independence, social integration and participation in the life of the community" by persons with disabilities.
- *Convention on the Rights of the Child* (CRC, 1990) implicitly recognizes the right to community living:

> *Where their family cannot provide the care they need, despite the provision of adequate support by the state, the child has the right to substitute family care (Article 20). Children with intellectual or physical disabilities have a right to live in "conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community" (Article 23). (European Expert Group, 2012, p. 18)*

Table A5 shows which of the thirteen countries considered in this study have ratified (R) or signed (S) these foundational human rights treaties.

TABLE A5.

Countries Signing (S) & Ratifying (R) Human Rights Treaties in Europe and Eurasia

Country	**United Nations Treaties** **CRC** (1990)	**United Nations Treaties** **CRPD** (2008)	**United Nations Treaties** **CRPD OP**	**Council of Europe Treaties** **ECHR** (1953)	**Council of Europe Treaties** **ESC** ('61, rev. '96)
Albania	R	S	—	R	R
Armenia	R	R	—	R	R
Azerbaijan	R	R	R	R	R
Belarus [a]	R	—	—	—	—
Bosnia and Herzegovina	R	R	R	R	R
Georgia	R	S	S	R	R
Kosovo [b]	—	—	—	—	—
Republic of Macedonia	R	R	R	R	R
Moldova	R	R	—	R	R
Montenegro	R	R	R	R	R
Russian Federation	R	R	—	R	R

Serbia	R	R	R	R	R
Ukraine	R	R	R	R	R

Notes: All countries covered by this report, with the exception of Belarus and Kosovo, are members of the Council of Europe, have ratified the ECHR and the ESC (1996), and have either signed or ratified the CRPD.

[a] Belarus is a member of the United Nations and has ratified the CRC.

[b] Kosovo has not signed or ratified any of these treaties because it is not yet a member of either the United Nations or the Council of Europe.

These standards support the right of people with disabilities to live in the community and their enabling recommendations and resolutions call for the development of community-based services for children and adults with disabilities. See The Common European Guidelines (European Expert Group, 2012) for an overview of the human rights treaties emanating from the Council of Europe and the United Nations related to community living (p. 34–43).

ANNEX 6: RESOURCES FOR THE TRANSITION TO COMMUNITY LIVING

Chiriacescu, Diana. 2008. *Shifting the Paradigm in Service Provision: Making Quality Services Accessible for People with Disabilities in South East Europe*. Disability Monitor Initiative. Retrieved from the Handicap International website: http://www.hiproweb.org/fileadmin/cdroms/Kit_Formation_Services/documents/Module-2/2-B-8_Shifting_the_Paradigm_in_Social_service_Provision.pdf

Fox, L. & Gotestam, R. 2003. *Redirecting Resources to Community-based Services: A Concept Paper*. Retrieved from http://tric.tomsk.gov.ru/files/2006/01/18/CD-Rom Content/pdfs/Papers/English/0311.pdf

Mulheir, G. & Browne, K. 2007. *De-Institutionalising and Transforming Children's Services: A Guide to Good Practice*. Retrieved from http://www.eurochild.org/fileadmin/user_upload/files/thematic_priorities/children_without_parental_care/Daphne_guide_on_deinstitutionalisation_-_July_2007.pdf

Open Society Public Health Program. 2011. *A Community for All Checklist: Implementing Article 19, A Guide for Monitoring Progress on the Implementation of Article 19 of the Convention on the Rights of Persons with Disabilities*. Retrieved from the Open Society Foundations website: http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf

SOS Children's Villages International and Council of Europe. 2009. *Children and young people in care. Discover your rights!* Retrieved from http://www.coe.int/t/dg3/children/childrenincare/C&YP%20IN%20CARE-ANGLAIS(web).pdf

UNICEF and World Bank. 2003. *Changing Minds, Policies and Lives: Improving Protection of Children in Eastern Europe and Central Asia. Gatekeeping Services for Vulnerable Children and Families*. Retrieved from the Innocenti Research Centre website: http://www.unicef-irc.org/publications/pdf/gatekeeping.pdf

UNICEF and World Bank. 2003. *Changing Minds, Policies and Lives: Improving Protection of Children in Eastern Europe and Central Asia. Improving Standards of Child Protection Services*. Retrieved from the Innocenti Research Centre website: http://www.unicef-irc.org/publications/pdf/improving.pdf

UNICEF. 2012. *Children Under the Age of Three in Formal Care in Eastern Europe and Central Asia: A Rights-Based Regional Situation Analysis*. Retrieved from http://www.crin.org/docs/UNICEF_Report_Children_Under_3_FINAL.pdf

UNICEF. 2013. *The State of the World's Children 2013: Children with Disabilities*. Retrieved from http://www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf

TOOLKITS

Better Care Network and UNICEF. 2009. *Manual for the Measurement of Indicators for Children in Formal Care*. Retrieved from http://www.unicef.org/protection/Formal_Care20Guide20FINAL.pdf

Cantwell, N. et al. 2012. *Moving Forward: Implementing the 'Guidelines for the Alternative Care of Children'*. UK: Centre for Excellence for Looked After Children in Scotland. Retrieved from http://www.alternativecareguidelines.org/Portals/46/Moving-forward/Moving-forward-implementing-the-guidelines-ENG.pdf

Financing Taskforce of the Global Health Workforce Alliance (GHWA) and World Bank. *The Resource Requirements Tool*. Retrieved from the WHO-GHWA website: http://www.who.int/workforcealliance/knowledge/resources/rrt/en/index.html

Lumos Foundation. *Toolkit for the Strategic Review of Children's Services*. For more information and training on the use of the *Toolkit*, contact info@lumos.org.uk

SOS Children's Villages International. 2012. *Assessment tool for the implementation of the UN Guidelines for the Alternative Care of Children*. Retrieved from the Child Rights International Network website: http://www.crin.org/docs/120412-assessment-tool-SOS-CV%20.pdf

SOS-Kinderdorf International. 2007. *Quality4Children standards for out-of-home child care in Europe*. An initiative by FICE, IFCO, and SOS Children's Villages. Retrieved from the Quality4Children website: http://www.quality4children.info/content/cms,id,89,nodeid,31,_language,en.html

World Health Organization. 2012. *WHO QualityRights Tool Kit: Assessing and improving quality and human rights in mental health and social care facilities*. Retrieved from http://whqlibdoc.who.int/publications/2012/9789241548410_eng.pdf

World Health Organization. 2013. Choosing Interventions that are Cost Effective (WHO-CHOICE) database on the costs, impact on population health, and cost-effectiveness of interventions for mental health in Europe. Retrieved from the WHO website: http://www.who.int/choice/en/

Full references for the following transition resources already appear in the References:

Common European Guidelines on the Transition from Institutional to Community-based Care.

Deinstitutionalisation and community living – outcomes and costs: report of a European Study.

Early Childhood Development, What Parliamentarians Need to Know.

Forgotten Europeans – Forgotten Rights: The Human Rights of Persons Placed in Institutions.

Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care.

The Rights of Vulnerable Children Under the Age of Three – ending their placement in institutional care.

Toolkit for Improving Standards of Child Protection Services in ECA Countries.

Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities.