

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





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

Guidance on implementing and supporting  
a sustained transition from institutional care to family-based  
and community-based alternatives for children, persons with  
disabilities, persons with mental health problems  
and older persons in Europe

The Common European Guidelines on the Transition from Institutional to Community-based Care and the Toolkit on the Use of European Funds for the Transition from Institutional to Community-based Care are available in English and a number of other languages at [www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu)





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# Foreword

Across the European Union, hundreds of thousands of people with disabilities, mental health problems, older people or abandoned and vulnerable children live in large segregating residential institutions.

Such institutions were originally created to provide care, food and shelter, but by now evidence has shown that they cannot ensure person-centred services and appropriate support needed to bring about full inclusion. The physical separation from communities and families severely limits the capacity and preparedness of those living in or growing up in institutions to participate fully in their community and wider society.

The shared European values of human dignity, equality and the respect for human rights should guide us as our societies develop structures of social care and support fit for the 21st century. The European Commission takes an active role in helping the less advantaged. The Europe 2020 strategy has set ambitious targets for inclusive growth requiring action to be taken to promote integration and adequate livelihood of poor and excluded people.

The present *Guidelines* and *Toolkit* are the result of an initiative taken by our predecessor, Vladimír Špidla, then EU Commissioner for Employment, Social Affairs and Equal Opportunities. He initiated to set up a group of experts on the Transition from Institutional to Community-based Care and asked them to report on basic principles and priority recommendations. Key among those recommendations was the need to develop detailed common European Guidelines and a Toolkit on the Transition from Institutional to Community-Based Care which now have become reality after a year-long process of consultation and gathering of good practice and expertise from across Europe.

But with this important milestone achieved, the implementation of adequate reforms of care systems needs to take place in Member States. The Commission will support those efforts by continuing the monitoring of the recent trends in poverty and inequality while forecasting the implications of policy measures. This is done as part of the Europe 2020 strategy during the so-called European Semester. This process helps assisting Member States in carrying out structural reforms that promote inclusive growth. The Structural Funds make an important contribution to implement these reforms, support social economy and more efficient policies. Furthermore, for the next financing period the Commission has proposed minimum shares per category of regions resulting in at least 25% of cohesion policy resources to human capital and social investment by the ESF, and at least 20% of this amount to social inclusion. De-institutionalisation is one of the proposed priorities.

We congratulate the authors on this very welcome publication which will serve as an extremely useful input as regards the use of structural funds for de-institutionalisation both in the current and also in the new 2014–2020 programming period.

László Andor

Commissioner for Employment, Social Affairs and Inclusion

Johannes Hahn

Commissioner for Regional Policy









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# Executive Summary

## I. Purpose and scope of the Guidelines

The Common European Guidelines on the Transition from Institutional to Community-based Care ('the Guidelines') provide practical advice about how to make a sustained transition from institutional care to family-based and community-based alternatives for individuals currently living in institutions and those living in the community, often without adequate support.

The Guidelines are based on European and international best practice and have been developed in consultation with key European networks representing children, people with disabilities, mental health organisations, families, older people and public and non-profit service providers. Senior public servants from several countries, as well as a number of European Commission officials, have also been consulted in order to ensure that the Guidelines respond to needs at a grassroots level. A range of professionals with expertise in all aspects of the transition from institutional to community-based care were also consulted.

## II. Who should read the Guidelines

The Guidelines are aimed primarily at policy and decision makers in the European Union and the neighbouring countries with responsibility for the provision of care and support services for:

- children;
- people with disabilities and their families;
- people with mental health problems; and
- older people.

To enable full social inclusion, the Guidelines also target politicians and senior civil servants dealing with other policy areas such as health, housing, education, culture, employment and transport. They can be used at all levels, including by municipalities and regions responsible for local service provision and management.

The Guidelines are also intended for use by the European Commission officials with responsibility for overseeing the use of Structural Funds and other EU funding instruments in the Member States and neighbouring countries, as well as those responsible for EU social policy and the implementation of the Social Agenda. It is intended that the Guidelines are used alongside the Toolkit on the use of European Union funds for the transition from institutional to community-based care (the Toolkit, available at [www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu)).<sup>1</sup>

<sup>1</sup> These guidelines have been developed on the basis of the recommendation in the *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care* (2009) Brussels: European Commission, p.8. In the remainder of the chapter, this report will be referred to as the "*Ad Hoc Expert Group report*". See p.21 for further information.

### III. Introduction

More than one million children and adults live in institutions across Europe.<sup>2</sup> Institutions were once seen as the best way of caring for vulnerable children, children at risk and adults with a variety of support needs. However, evidence has shown that institutional care invariably provides poorer outcomes in terms of quality of life than quality services in the community, often amounting to a lifetime of social exclusion and segregation.<sup>3</sup> Scientific research into children's early development shows that, when it comes to very young children, even a relatively short institutional placement can negatively affect brain development and have life-long consequences on emotional well-being and behaviour.<sup>4</sup> For these reasons and as a result of the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) and other human rights instruments, institutionalisation is increasingly acknowledged as poor policy and a violation of human rights.

#### KEY GUIDANCE 1: WHAT IS "AN INSTITUTION"?

The Guidelines define an institution as any residential care where:

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have sufficient control over their lives and over decisions which affect them; and
- the requirements of the organisation itself tend to take precedence over the residents' individual needs.<sup>5</sup>

Many countries have embarked on the process of transforming the way they provide care and support to children and adults by replacing some or all long-stay residential institutions with family- and community-based services. A key challenge is ensuring that the process of deinstitutionalisation itself is carried out in a way that respects the rights of the user groups, minimises risk of harm and ensures positive outcomes for all individuals involved. The process needs to ensure that the new systems of care and support respect the rights, dignity, needs and wishes of each individual and their family.

2 Children and adults with disabilities (including people with mental health problems). It covers the EU and Turkey from Mansell, J., Knapp, M., Beadle-Brown, J. & Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent (hereafter, "DECLOC Report").

3 Smyke, A.T. et al. (2007) 'The caregiving context in institution-reared and family-reared infants and toddlers in Romania' in *Journal of Child Psychology and Psychiatry* 48:2 (2007) pp.210–218 – Greece – Vorria et al. (2003), UK – Tizard & Rees (1974) and US – Harden (2002); Pashkina (2001). *Sotsial'noe obespechenie*, 11:42–45. Cited in Holm-Hansen, J., Kristofersen, L.B. & Myrvold, T.M. (eds.) *Orphans in Russia*. Oslo, Norwegian Institute for Urban and Regional Research (NIBR-rapport 2003:1); Rutter, M. et al. (1998). 'Developmental catch-up, and deficit, following adoption after severe global early privation' in *Journal of Child Psychology & Psychiatry*, 39(4):465–476.

4 Bowlby, J. (1951). *Maternal care and mental health*. Geneva, World Health Organisation; Matějček, Z. & Langmeier, J. (1964). *Psychická deprivace v dětství* [Mental deprivation in childhood]. Prague, Avicenum.; Nelson, C. & Koga, S. (2004) 'Effects of institutionalisation on brain and behavioural development in young children: Findings from the Bucharest early intervention project', paper presented at the *International Conference on Mapping the number and characteristics of children under three in institutions across Europe at risk of harm*, 19 March 2004, EU Daphne Programme 2002/3 and WHO Regional Office for Europe, Copenhagen, Denmark; Rutter, M. et al. *op. cit.*, pp.465–476.

5 *Ad Hoc Expert Group Report*.

**Key lessons that have emerged over the years include:**

- the importance of a vision;
- the need to engage with civil society;
- the need to bring all the stakeholders on board; and
- the crucial role of leadership in driving this process.

## **IV. Moving from institutional care to community-based services**

### **CHAPTER 1:**

#### **Making the case for developing community-based alternatives to institutions**

This chapter provides an overview of the support for the transition from institutional care to community-based services at the European and international level. It covers human rights and values, political commitments and scientific and economic evidence. The purpose of this chapter is to provide governments with evidence to support deinstitutionalisation<sup>6</sup> and demonstrate how it can benefit not just the people concerned, but society as a whole. Governments and other stakeholders may draw on this evidence to build a case for transition, tailoring it to their national context. This will enable them to take collective ownership of the process.

**Key components:**

- ▶ Prevalence of institutional care in Europe
- ▶ Political commitment to the development of community-based alternatives to institutional care
- ▶ Human rights violations in institutional care
- ▶ Damaging effects of institutionalisation
- ▶ Use of resources in community-based systems

### **CHAPTER 2:**

#### **Assessment of the situation**

An assessment of the situation is central to the development of a comprehensive deinstitutionalisation strategy and action plan which will address genuine needs and problems and make good use of available resources. This chapter explains why barriers to accessing mainstream community services should also be examined if the goal is to ensure full inclusion of children, people with disabilities, people with mental health problems, and older people into society.

**Key components:**

- ▶ System analysis
- ▶ Assessment of resources
- ▶ Information on existing community-based services

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6 Deinstitutionalisation refers to the process of developing a range of services in the community, including prevention, in order to eliminate the need for institutional care. See p.28 for more detail.



## CHAPTER 3: Developing a strategy and an action plan

The development of a strategy and action plan for deinstitutionalisation and community-based services should draw on the situation analysis. This chapter shows how a strategy and plan can support coordinated and systemic reform, both on a local and national level.

### Key components:

- ▶ Involving participants in the process
- ▶ Developing a strategy
- ▶ Developing an action plan

## CHAPTER 4: Establishing the legal framework for community-based services

Once the decision to replace institutions with family- and community-based alternatives has been made, it is important to build legislative support for the inclusion of all user groups into society. During this process it is recommended the existing legislation and policies be reviewed. Any obstacles to the provision of high-quality, family-based care and services in the community, as well as obstacles to accessing mainstream services or to participation in society and user involvement, should be removed. They should be replaced with legislation and policies that support family and community inclusion and participation.

### Key components:

- ▶ The right to live in the community
- ▶ Access to mainstream services and facilities
- ▶ Legal capacity and guardianship
- ▶ Involuntary placement and involuntary treatment
- ▶ Provision of community-based services

## CHAPTER 5: Developing a range of services in the community

Chapter 5 considers different types of community-based services needed for various user groups. With regard to children, it stresses the need for strategies that prevent family separation, promote family reintegration and encourage the development of high-quality, family-based options for alternative care. In relation to other user groups, it highlights the importance of community-based services for independent living and living arrangements that enable users to make choices and have more control over their lives.

### Key components:

- ▶ Principles of service development and delivery
- ▶ Preventing institutionalisation
- ▶ Prevention strategy measures
- ▶ Developing community-based services
- ▶ Living arrangements



## CHAPTER 6: Allocating financial, material and human resources

This chapter considers the resource implications – financial, material and human – of moving from institutional to community-based care. Because of its complexity, this process requires careful planning, coordination and control. For reform to go ahead, it is crucial that funding commitments are built into policies, that deinstitutionalisation plans use all available resources and that any additional resources required are identified.

### Key components:

- ▶ Planning – the interconnection between costs, needs and outcomes
- ▶ Workforce considerations and the need for skilled personnel
- ▶ Funding the new services
- ▶ Turning barriers into opportunities

## CHAPTER 7: Developing individual plans

The purpose of the individual plan is to ensure consistency between what a person needs, how they wish to live their life and the support they receive. This chapter examines different elements of the planning process and highlights the importance of ensuring the meaningful participation of users and (where relevant) their families and carers at all stages of the planning process.

### Key components:

- ▶ Involving users in decisions about their future
- ▶ Conducting individual assessments
- ▶ Developing individual care and support plans
- ▶ Challenges in the planning process

## CHAPTER 8: Supporting the individuals and communities during transition

The transition to the community is not merely a case of moving people physically from the institution to their new place of living or care placement. In order to avoid re-institutionalisation and to ensure the best possible outcomes for people using the services, the move should be prepared with great care. Chapter 8 provides ideas on preparing and supporting this transition process. It also highlights the importance of working with the carers and communities.

### Key components:

- ▶ Supporting service users in transition
- ▶ Supporting carers
- ▶ Working with communities and managing resistance to transition

## CHAPTER 9: Defining, monitoring and evaluating the quality of services

Both during the transition from institutional care to community-based services and once the services are in place, it is crucial that institutional practices are not replicated in the community. This chapter sets out criteria that can be used to measure the quality of the services. It highlights the need for ongoing monitoring and evaluation of services and presents ways in which service users can be involved in service evaluation.

### Key components:

- ▶ Importance of defining quality standards
- ▶ Implementing standards at different levels of governance
- ▶ Defining the content of quality standards
- ▶ Developing policies and strategies for monitoring and evaluation
- ▶ Inspecting and evaluating institutional care

## CHAPTER 10: Developing the workforce

There is a strong link between personnel and the successful development and maintenance of quality services in the community. The availability of well-trained and motivated personnel in a community affects how quickly new services can be put in place and can ensure that institutional practices are not replicated in community settings. The final chapter sets out a process of workforce development which countries can follow in moving from institutional to community-based services in order to sustain the provision of quality services in the community.

### Key components:

- ▶ Planning – identifying skills, roles and processes
- ▶ Selection of personnel
- ▶ Training and re-training
- ▶ Professional values and ethics of the social work professionals
- ▶ Barriers to workforce development





# I. Preface

## Purpose and scope of the Guidelines

The Common European Guidelines on the Transition from Institutional to Community-based Care ('the Guidelines') provide practical advice about how to make a sustained transition from institutional care to family- and community-based alternatives for individuals currently living in institutions and those living in the community, often without adequate support (see Key guidance 2, below).

The Guidelines are based on European and international best practice and have been developed in consultation with key European networks representing children, people with disabilities, mental health organisations, families, older people and public and non-profit service providers. Senior public servants from several countries as well as a number of European Commission officials have also been consulted in order to ensure that the Guidelines respond to needs at the grassroots level. Experts in the transition from institutional to community-based care provided advice on specific aspects of the Guidelines.

What distinguishes the Guidelines from some other literature on deinstitutionalisation is its use of largely non-academic language to explain some of the key principles and elements of moving away from institutional care to community living. These can be used by policy and decision makers at national, regional and local levels, as well as by EU institutions, to plan and implement the transformation of care and support services, and to facilitate the inclusion of children, adults and older people with care and/or support needs into society. The Guidelines highlight the Member States' and EU's obligations under the UN Convention on the Rights of Persons with Disabilities, the UN Convention on the Rights of the Child and the European Convention on Human Rights. They show how the process set out in this document can help realise the rights set out in the conventions.

### KEY GUIDANCE 2: COMMUNITY AND FAMILY-BASED ALTERNATIVES

While the title of the Guidelines refers to community-based services, it should be understood to include both family- and community-based alternatives to institutional care. This is of crucial importance in relation to children, where family-based care should come before any alternative care arrangements. Therefore, in relation to children, 'transition from institutional to family- and community-based care and services' is the preferred terminology.





## Objectives of the Guidelines

- ▶ To raise awareness at EU level of the care and/or support needs of different groups and to draw attention to the better quality of life people could enjoy in the community.
- ▶ To offer expert advice to Member States, neighbouring countries and EU institutions, and gather good practice examples on the transition from institutional care to community-based services.
- ▶ To highlight person-centred approaches in the design and delivery of care and support services.
- ▶ To encourage Member States to fully involve user groups and, where appropriate, their families and carers, as well as other stakeholders such as service providers, public authorities, civil society, the research community and other networks of change, both within their borders and internationally.
- ▶ To point out the changes needed in societies in order to make public services such as health care, education, transport, housing etc at community level inclusive and accessible for everyone, regardless of their impairment, level of dependency or disability-related needs.
- ▶ To demonstrate the ethical, social, cultural and economic value of high-quality family- and community-based care and support.
- ▶ To ensure that EU and national policies and funding mechanisms support the transition from institutional care to community-based services, including prevention and family-based care for children, in response to both existing and future needs.

## Who should read the Guidelines?

The Guidelines are aimed primarily at policy and decision-makers in the European Union and neighbouring countries with responsibility for the provision of care and support services for children, people with disabilities and their families, people with mental health problems and older people.

To enable full social inclusion, the Guidelines also target politicians and senior civil servants dealing with other policy areas, such as health, housing, education, culture, employment and transport. They can be used at all levels, including local authorities and regions responsible for local service provision and management.

The Guidelines are also intended for use by European Commission officials with responsibility for overseeing the use of Structural Funds and other EU funding instruments in the Member States and neighbouring countries, as well as those responsible for EU social policy and the implementation of the Social Agenda. They should be used alongside the *Toolkit on the use of European Union funds for the transition from institutional to community-based care* ('the Toolkit'), which is based on the draft Structural Funds Regulation 2014–2020.<sup>7</sup> The Toolkit provides an overview of the three stages of Structural Funds management – programming, implementation, monitoring and evaluation – explaining what should be done at each stage by the Managing Authorities, Monitoring Committees and/or European Commission to ensure that EU funding supports the development of community-based alternatives to institutionalisation.

The Guidelines encompass the four user groups that are commonly placed into institutional care:

- children with and without disabilities;
- people with disabilities;
- people with mental health problems; and
- older people.

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<sup>7</sup> COM(2011) 615 final/2.





Wherever possible, the four user groups are treated together in order to make the Guidelines more user friendly. However, issues specific to individual user groups are dealt with separately to reflect the situation in practice, where it is necessary to recognise and acknowledge the differences between the various groups and their specific requirements for care and/or support.

## How to use the Guidelines

The European Expert Group recognises that the transition from institutional care to community-based services is a complex process and not all countries are starting from the same position. The Guidelines therefore deliberately avoid using a step-by-step approach. Instead, they outline different elements of the process and show how they are interconnected. While the aim is not to be overly prescriptive, the order of the chapters suggests the possible starting point for reform, i.e. the development of a strategy and an action plan based on the assessment of the situation.

Much is known about what does and what does not work in transforming the systems of care and support, yet countries often fail to learn from each other's experiences. The Guidelines include some potential risks, as well as challenges and barriers, to developing high-quality services in the community. It is hoped that these will inform future plans and actions.

### Why are obligations under the UN Convention on the Rights of Persons with Disabilities (CRPD) included in the chapters?

In each chapter a reference is made to the relevant article(s) of the UN Convention on the Rights of Persons with Disabilities (CRPD), and the obligations that follow for State Parties to the Convention.<sup>8</sup> Even though the CRPD is not the only international human rights instrument relevant to the Guidelines (there are many more, as listed in Chapter 1) it is the only one explicitly recognising the right to live independently in the community. Article 19 (see below), requires States to ensure that people with disabilities have access to community services “necessary to support living and inclusion in the community; and to prevent isolation or segregation from the community”. This cannot be achieved if countries continue to place individuals in institutional care.

The CRPD is relevant to a broad group of individuals: children and adults with disabilities, people with mental health problems and older people with disabilities. It can also be argued that the obligation to ensure individuals can live in the community, with choices equal to others, extends to other groups, such as children and older people without disabilities. “While not all children and older persons living in institutions will have disabilities, the new approach contained in the CRPD is likely to have an impact on members of other groups who are placed in institutions. [...] Although the CRPD is specific to persons with disabilities, Article 19 is founded on rights that apply to everyone.”<sup>9</sup> This is because the CRPD does not create new rights – proclaimed already in the Universal Declaration on Human Rights, the International Covenant on Civil and Political Rights and other instruments – and is founded on the principles of universality and indivisibility of human rights.

These Guidelines should therefore be used by countries and the European Union as a tool to implement the CRPD.

8 The list of countries that ratified the CRPD and the Optional Protocol is available at: <http://www.un.org/disabilities/countries.asp?id=166>

9 OHCHR (2010) *Forgotten Europeans – Forgotten Rights: The Human Rights of Persons Placed in Institutions*. Geneva: OHCHR, p.7.





## Article 19 – Living independently and being included in the community

States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall 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, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; and
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

## Why are obligations under the UN Convention on the Rights of the Child (CRC) included in the chapters?

The CRC states that “for the full and harmonious development of his or her personality” the child should “grow up in a family environment, in an atmosphere of happiness, love and understanding”. In addition, it outlines a range of children’s rights that, taken together, suggest that most children should live with and be cared for by their birth families (Articles 9 and 7). It is the primary responsibility of parents to raise their children and it is the responsibility of the state to support parents in order that they can fulfil that responsibility (Article 18). Children have the right to protection from harm and abuse (Article 19), to an education (Article 28) and to adequate healthcare (Article 24) but they simultaneously have the right to be raised by their family. 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).<sup>10</sup> 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).

10 Mulheir, G. & Browne, K. (2007) *De-institutionalising and Transforming Children’s Services. A Guide to Good Practice*. University of Birmingham: Birmingham.





### Why are obligations under the European Convention on Human Rights (ECHR) included in the chapters?

Parties to the ECHR have an obligation to secure human rights for everyone within their jurisdiction.<sup>11</sup> The Convention is of great significance as it is legally binding and sanctions can be applied if a right is infringed upon.

Article 3 states that “No one shall be subjected to torture or to inhuman or degrading treatment or punishment” without any exceptions. Infringement of this Article may occur where the practices of an institution have such an impact on the person’s life that the threshold is met.

Article 8 of the ECHR guarantees the right to respect for private and family life and requires that any interference with this right by a public authority be justified as being in accordance with the law and necessary in a democratic society. This Article can, for example, be applied in cases where children are arbitrarily separated from their family or where a placement interferes with the child’s or adult’s ability to remain in contact with their family.

## European Expert Group on the Transition from Institutional to Community-based Care

The Guidelines and the accompanying publications (the Toolkit and the Training module) have been produced by the European Expert Group on the Transition from Institutional to Community-based Care. This group, formerly known as the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, was convened in February 2009 by the then Commissioner for Employment and Social Affairs Vladimír Špidla in order to address the issues of institutional care reform in the European Union. Its establishment was preceded by two major Commission-funded reports on the institutionalisation of children and adults with disabilities in the EU – *Included in Society*<sup>12</sup> and *Deinstitutionalisation and Community Living: Outcomes and Costs*<sup>13</sup>.

The Group consists of organisations representing children, families, people with disabilities, mental health organisations, public and non-profit service providers, public authorities and intergovernmental organisations. They are COFACE (Confederation of Family Organisations in the EU), EASPD (European Association of Service Providers for Persons with Disabilities), EDF (European Disability Forum), ENIL/ECCL (European Network on Independent Living/European Coalition for Community Living), ESN (European Social Network), Eurochild, Inclusion Europe, Lumos, MHE (Mental Health Europe), OHCHR (Office of the High Commissioner for Human Rights, Europe Regional Office) and UNICEF.<sup>14</sup>

At the end of 2009, the Group published an influential report setting out the ‘Common Basic Principles’ of deinstitutionalisation together with recommendations for the Member States and the European Commission. The *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care* was endorsed by Commissioner Špidla and translated into all EU

11 Article 1.

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

13 DECLOC Report.

14 Shortly before finalisation of these Guidelines, the Group was joined by the European Federation of National Organisations Working with the Homeless (FEANTSA).





languages.<sup>15</sup> Since its publication, the Report has been used by several Governments in preparation of their strategies and action plans, as well as by non-governmental organisations (NGOs)<sup>16</sup> and other advocates for community living. One of the key recommendations of the report, particularly welcomed by Commissioner Špidla and other EC officials, was the production of Guidelines to explain in practical terms how to move from institutional care to community living and to highlight the main challenges and possible solutions.

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15 The report is available in English at <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes> or in other languages by request.

16 In some countries described as charities or 'non-profits'.





## II. Introduction

More than one million children and adults live in institutions across Europe.<sup>17</sup> Institutions were once seen as the best way of caring for vulnerable children, children at risk and adults with a variety of support needs. However, evidence has shown that institutional care invariably provides poorer outcomes than high-quality services in the community, often leading to a lifetime of social exclusion and segregation.<sup>18</sup> Scientific research shows that even a relatively short institutional placement can negatively affect brain development in very young children and have life-long consequences on their emotional well-being and behaviour.<sup>19</sup> For these reasons, and as a result of the adoption of the CRPD, the CRC, ECHR and other human rights instruments, institutionalisation is increasingly acknowledged as poor policy and a violation of human rights.

Developing quality community-based services is a matter of achieving respect for human rights and a good quality of life for all those who require care and/or support. All European countries have an obligation to ensure that every child is able to enjoy a standard of living adequate for their physical, mental and social development,<sup>20</sup> respecting the principle that all children should grow up in a family environment, in an atmosphere of happiness, love and understanding.<sup>21</sup> Furthermore, Article 8 of the ECHR guarantees the right to respect for private and family life to all citizens. Institutionalisation at any age interferes with this right. People with disabilities have a right to live independently and to be included in the community.<sup>22</sup> This right, enshrined in the CRPD, extends to everyone regardless of their age, ability or the nature of their impairment or mental health problem. It means that everyone should have the opportunity to live and participate in the community they choose. They should be involved in decisions about the care and/or support they receive and have maximum control over their lives. This vision of what people can achieve in their lives if appropriate support is in place should be at the heart of national, regional and local plans for the transition from institutional to community-based care.<sup>23</sup>

Many countries have embarked on the process of transforming the way they provide care and support to children and adults and have replaced some or all long-stay residential institutions with family and community-based services. The challenge in this process has been ensuring that the

17 Children and adults with disabilities (including people with mental health problems). It covers the EU and Turkey, from *DECLOC Report*.

18 Smyke, A. T. et al. *op. cit.*, pp.210-218 – Greece – Vorría et al. (2003), UK – Tizard & Rees (1974) and US – Harden (2002); Pashkina *op. cit.*, pp.42-45; Rutter, M. et al. *op. cit.*, pp.465– 476.

19 Bowlby, J. *op. cit.*; Matějček, Z. & Langmeier, J. *op. cit.*; Nelson, C. & Koga, S. *op. cit.*; Rutter, M. et al. *op. cit.*, pp.465– 476.

20 United Nations Convention on the Rights of the Child, Article 27.

21 Preamble to United Nations Convention on the Rights of the Child.

22 United Nations Convention on the Rights of Persons with Disabilities, Article 19.

23 *DECLOC Report*, p.52.





new systems of care and support respect the rights, dignity, needs and wishes of each individual and their family.<sup>24</sup> Some of the lessons that have emerged over the years are: the importance of a vision, the need to engage with civil society, the need to bring all stakeholders on board and the crucial role of leadership in driving this process.

## Vision for change

*“Key ingredients for the successful replacement of institutional by community care are a national (or perhaps regional) policy framework and detailed local plans for transferring care out of an institution and into a well-prepared community, both of which should embody positive but realistic visions for the future lives of individual people”.*<sup>25</sup>

Those countries that have moved from institutional to community-based care<sup>26</sup> have found that having a strategic vision of holistic reform is one of the most important factors behind the process. This vision will ideally be shaped by central government but must involve all the stakeholders in the system, from local authorities to organisations representing service users. It should incorporate incentives for change and promote positive examples of good practice. These include measures such as a moratorium on the building of new institutions and redirecting resources from institutions to deliver support services in the community.<sup>27</sup>

## Engaging with users and providers

When developing the strategic vision, it is crucial that the government works with people who will ultimately be using the services, their representative organisations and their families. While it is important to involve service providers, the rights and views of the users of services should always come first. In countries where governments have committed to moving from a system of institutional to community-based support, it has often been in response to calls for reform by these key stakeholders.

In terms of sustaining the process of reform, organisations representing children, people with disabilities, people with mental health problems and older people have a crucial role to play. A complete transition from institutional care to community-based services may take years, and it is likely that national and local government administrations will change during the process. There is a danger that a new government may not continue the reform or may revert to the old system. A strong and committed civil society movement can bring the process back on track and ensure it is carried out as planned. An important aspect of the role of civil society is to lobby for cross-party support for the transition from institutional to community based care, minimising the impact of a change in administration.

24 In the majority of cases, a family is the main support network in an individual's life and therefore should be involved in decisions about the care and/or support provided. It should be noted, however, that there are cases where the interests of the family are in conflict with the interest of the service user, or there may be other reasons why the family should not be involved. The primary consideration should always be the service user's interests, and their needs and wishes.

25 DECLOC Report, p.52.

26 In Europe, Scandinavian countries (especially Sweden) and the UK are considered to be leaders in this field. When it comes to long-term care for older people, countries like Denmark have made great progress in developing community-based services.

27 Power, Andrew (2011) *Active Citizenship & Disability: Learning Lessons in Transforming Support for Persons with Disabilities*. Galway: National University of Ireland Galway, p.15.





## Stakeholder involvement

During the planning process, it is important that no stakeholder is seen as a barrier or hindrance.<sup>28</sup> Rather, it is vital that everyone is brought on board, including service users, families, service providers and personnel, local authorities, trade unions and local communities, to address concerns and dispel myths. Building a shared vision of the inclusion of different groups in the community and the right to live independently is an important step in achieving this objective. Adopting this approach will ensure there is local ownership of the process and should result in a strong commitment to improving people's lives.

## Leadership to drive change

In countries that have made good progress in the transition to community-based services, the importance of leadership has been crucial.<sup>29</sup> The complexity of the process and the diversity of stakeholders involved can lead to 'reorganisation fatigue': disillusionment about the change and a lack of motivation to support it. Political and professional leadership at different levels is therefore needed to drive change. Good leadership is characterised by a willingness to work in partnership with others. In a process in which resistance and conflict are to be expected, good leaders can drive the reform and negotiate with others without compromising on the main objectives.

To encourage leadership, countries can provide various incentives such as innovation grants to support those willing to try new initiatives.<sup>30</sup>

### KEY GUIDANCE 3: TEN LESSONS ON HOW TO ACHIEVE COMMUNITY LIVING<sup>31</sup>

1. Ensure that champions for community living are involved in leading change.
2. Make the needs and preferences of people central to planning.
3. Respect the experiences and roles of families.
4. Create a real home and personalised support for each individual.
5. Focus on achieving quality services and ensuring people can lead their own lives safely.
6. Recruit and develop skilled personnel.
7. Engage a broad partnership in delivering change.
8. Establish a clear plan and timescale for creating the community services necessary to make each institution redundant.
9. Invest in communicating all this effectively to everyone affected, including in the communities to which people are moving.
10. Support each person in their transition to community living.

<sup>28</sup> *Ibid.*, p.15.

<sup>29</sup> *Ibid.*, pp.17–18.

<sup>30</sup> For example, see the Genio Trust in Ireland: <http://www.genio.ie/>

<sup>31</sup> Extract from People First of Canada/Canadian Association for Community Living (2010) *The Right Way – A Guide to closing institutions and reclaiming a life in the community for people with intellectual disabilities*, available at: [http://www.institutionwatch.ca/cms-filesystem-action?file=resources/the\\_right\\_way.pdf](http://www.institutionwatch.ca/cms-filesystem-action?file=resources/the_right_way.pdf)







## III. Definition of key terms

### 1. 'An institution'

There are different understandings of what constitutes 'an institution' or 'institutional care' depending on the country's legal and cultural framework. For this reason, the Guidelines use the same approach as in the Ad Hoc Report.<sup>32</sup> Rather than defining an institution by size, i.e. the number of residents, the Ad Hoc Report referred to 'institutional culture'. Thus, we can consider 'an institution' as any residential care where:

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have sufficient control over their lives and over decisions which affect them; and
- the requirements of the organisation itself tend to take precedence over the residents' individualised needs.

At the same time, size is an important factor when developing new services in the community. Smaller and more personalised living arrangements are more likely to ensure opportunities for choice and self-determination of service users<sup>33</sup> and to provide a needs-led service. When developing strategies for transition from institutional care to community-based services, some countries decide to limit the maximum number of users that can be accommodated in the same setting, such as number of residents in apartment or a building.<sup>34</sup> This approach can help to ensure that institutional culture is not recreated in the new services.

It must be noted, however, that the small size of accommodation does not in itself guarantee elimination of institutional culture in the setting. There are a number of other factors, such as the level of choice exercised by the service users, the level and quality of support provided, participation in the community and quality assurance systems used which impact on the quality of the service. In some cases, people can be coerced into taking certain treatment in order to have access to services in the community.<sup>35</sup> In such cases, institutional culture prevails despite the fact that the service itself may not be institutional in character.

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32 *Ad Hoc Expert Group Report.*

33 Health Service Executive (2011) *Time to Move on from Congregated Settings: A Strategy for Community Inclusion*, Report of the Working Group on Congregated Settings, p.68.

34 In Sweden, for example, community-based accommodation is designed to accommodate a maximum of six individual units or apartments and must be situated in ordinary buildings. (See Townsley, R. et al. (2010), *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report*. Brussels: ANED, p.19).

35 See, for example Szmukler, G. & Appelbaum, P., *Treatment pressures, leverage, coercion, and compulsion in mental health care*, Journal of Mental Health, 17(3), June 2008, pp.233–244.



## 1.1 Institutions for persons with mental health problems

Institutions in the psychiatric field are, in many ways, different from social care homes and other types of long-stay residential institutions for other groups. Residential settings for people with mental health problems tend to have a predominantly medical character. These are often psychiatric hospitals or psychiatric units in general hospitals run by medical personnel. The basis of admission is a psychiatric diagnosis and the treatment is also medical, conducted by psychiatrists and other medical personnel. In addition, mental health institutions are often financed by health authorities or are being run under health budgets and not social services. There should be a clear distinction between psychiatric treatment as a form of healthcare service provision, and institutionalisation as a form of social treatment towards or against persons with mental health problems. One of the main reasons for institutionalisation is the lack of social services in the community, leading to discrimination and social exclusion of people with mental health problems.

## 1.2 Institutions for children

There is no definition of 'institutions' in the UN Guidelines for the Alternative Care of Children; in the text of those Guidelines, they are equated with 'large residential facilities'.<sup>36</sup>

Based on the UN Guidelines and in the absence of a universally accepted definition, Eurochild suggests defining institutions for children "as (often large) residential settings that are not built around the needs of the child nor close to a family situation, and display the characteristics typical of institutional culture (depersonalisation, rigidity of routine, block treatment, social distance, dependence, lack of accountability, etc.)". An organised routine, an impersonal structure and a high child/care-giver ratio are additional characteristics mentioned.

When deciding on what is an institution, UNICEF looks at "whether the children have regular contact and enjoy the protection of their parents or other family or primary caregivers, and whether the majority of children in such facilities are likely to remain there for an indefinite period of time". They recognise, however, that no definition is all-encompassing and will depend on the context in different countries.<sup>37</sup>

There are different types of children's institutions, including 'infant homes', usually accommodating toddlers and young children up to the age of four, 'children's homes' and 'internats'.<sup>38</sup> Institutions for children are also referred to as 'orphanages', despite the fact that the majority of children they accommodate are not orphans.<sup>39</sup>

In many countries, children's institutions are divided across different departments and often take on the characteristics of the departments running them.<sup>40</sup> Often baby institutions are run by health departments and are medical in character. Mainstream children's homes and residential schools for children with disabilities are run by education departments and often focus primarily on education. Children with disabilities are usually the responsibility of Ministries of Social Affairs. In some countries these children are placed together in institutions for adults with disabilities, with little provision for protecting children from harm.

36 United Nations (2009) *Guidelines for the Alternative Care of Children*. New York: United Nations, para 23.

37 UNICEF *Consultation on Definitions of Formal Care for Children*, pp.12–13.

38 Browne, K. (2009) *The Risk of Harm to Young Children in Institutional Care*. London: Save the Children, p.2.

39 Mulheir, G. & Browne, K. *op. cit.*

40 *Ibid.*





The division of children's institutions across different departments often results in the separation of sibling groups and regular moves from one institution to another.<sup>41</sup>

## 2. 'Deinstitutionalisation'

Wherever possible, these Guidelines avoid using the term 'deinstitutionalisation', since it is often understood as simply the closure of institutions. In places where the term is used, it refers to the process of developing a range of services in the community, including prevention, in order to eliminate the need for institutional care.

UNICEF defines deinstitutionalisation as "the full process of planning transformation, downsizing and/or closure of residential institutions, while establishing a diversity of other child care services regulated by rights-based and outcomes-oriented standards."<sup>42</sup>

## 3. 'Community-based services'

In the Guidelines, the term 'community-based services', or 'community-based care', refers to the spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as personal assistance for persons with disabilities, respite care and others. In addition, the term includes family-based and family-like care for children, including substitute family care and preventative measures for early intervention and family support.

Community-based services are described in more detail in Chapter 5.

## 4. 'Prevention'

'Prevention' is an integral part of the process of transition from institutional to community-based care.

In the case of children, it includes a wide range of approaches that support family life and prevent the need for the child to be placed in alternative care, in other words to be separated from his/her immediate or extended family or other carer.<sup>43</sup>

In the case of adults, prevention refers to a wide range of support services for individuals and their families, with the aim of preventing the need for institutionalisation. In relation to older people, the focus should be on preventing ill health, the loss of function, and the restoration of independence. Prevention should encompass both mainstream and specialised services (see Chapter 5 for examples.)

41 Mulheir, G. & Browne, K. *op. cit.*

42 UNICEF (2010) *At Home or in a Home?: Formal Care and Adoption of Children in Eastern Europe and Central Asia*, p.52.

43 Save the Children UK (2007), *Child Protection and Care Related Definitions*, p.11.



## 5. ‘Alternative care’

‘Alternative care’ refers to 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.

Alternative care is also defined as “a formal or informal arrangement whereby a child is looked after at least overnight outside the parental home, either by decision of a judicial or administrative authority or duly accredited body, or at the initiative of the child, his/her parent(s) or primary caregivers, or spontaneously by a care provider in the absence of parents. This includes informal fostering by family or non-relatives, formal foster care placements, other forms of family-based or family-like care placements, places of safety for emergency child care, transit centres in emergency situations, other short and long term residential care facilities including group homes and supervised independent living arrangements for children”.<sup>44</sup>

There is no explicit definition of what distinguishes ‘family-based care’ from ‘family-like care’ in the UN Guidelines, although both are seen as distinct from residential care. In developing community-based services for children, the following definitions may be helpful.<sup>45</sup>

Family-based care	Family-like care
A short- or long-term care arrangement agreed with, but not ordered by, a competent authority, whereby a child is placed in the domestic environment of a family whose head(s) have been selected and prepared to provide such care, and who are financially and non-financially supported in doing so.	Arrangements whereby children are cared for in small groups in a manner and under conditions that resemble those of an autonomous family, with one or more specific parental figures as caregivers, but not in those persons’ usual domestic environment.

## 6. ‘Independent living’

### TESTIMONIAL 1: INDEPENDENT LIVING

*“What does independent living mean to me? I think that is a very deep, life changing question and it means a lot of things. I suppose I could say it has changed my life and I know it has changed the lives of many other disabled people whom I have come into contact with [...] It is very hard I think to get that message across to people who perhaps are not dependent on others to support them in their day-to-day living. But it has provided me with a life, my work (I have worked widely) and the opportunities and the choices to do the things I want, like you do. I think with the restrictions somebody like myself has, with the kind of severe impairment I have, it is freedom. It is the freedom for me to be able to do what I want to do, when I want to do it in a way, because I have people around me who can support me to do that”.<sup>46</sup>*

<sup>44</sup> *Ibid.*, p.2.

<sup>45</sup> Cantwell, Nigel (2010) *Refining definitions of formal alternative child-care settings: A discussion paper*.

<sup>46</sup> A quote by John Evans OBE, a member of the Expert Group on the Transition from Institutional to Community-based Care in the Joint Committee of Human Rights (2012), *Implementation of the Right of Disabled People to Independent Living*. London: House of Lords, House of Commons, p.10.





The term ‘independent living’ is often used interchangeably with ‘community living’ in relation to people with disabilities and older people. It does not mean ‘doing things for yourself’ or being ‘self-sufficient’. Independent living refers to people being able to make choices and decisions as to where they live, who they live with and how they organise their daily life. This requires:

- accessibility of the built environment;
- accessible transport;
- availability of technical aids;
- accessibility of information and communication;
- access to personal assistance, as well as life and job coaching; and
- access to community-based services.<sup>47</sup>

It also implies the recognition of, and support for, family carers, including the need to help maintain or improve their quality of life.<sup>48</sup>

In the case of children, independent living is used to refer to ‘supervised independent living arrangements’ and would only involve children aged 16 or older. These are settings where children and young people are accommodated in the community, living alone or in a small group home, where they are encouraged and enabled to acquire the necessary independent living skills.<sup>49</sup>

## 7. ‘User groups and families’

The Guidelines encompass four ‘user groups’:

- children (with and without disabilities);
- persons with disabilities;
- persons with mental health problems; and
- older people.

In the UN Convention on the Rights of the Child, a child is defined as “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier”.<sup>50</sup>

The UN Convention on the Rights of Persons with Disabilities defines ‘persons with disabilities’ as including “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”<sup>51</sup>

The term ‘persons with mental health problems’ refers to those who have received psychiatric diagnoses and treatment. Even though they are included in the definition of persons with disabilities in the CRPD, it should be noted that many do not identify as disabled. In these Guidelines, however, the term ‘persons with disabilities’ should also be understood as including persons with mental health problems.

47 European Network on Independent Living (2009) *ENIL's Key definitions in the Independent Living area*, available at: <http://www.enil.eu/policy/>

48 See COFACE, European Charter for Family Carers, available at: <http://www.coface-eu.org/en/Policies/Disability-Dependency/Family-Carers/>

49 Cantwell, Nigel *op. cit.*

50 United Nations Convention on the Rights of the Child, Article 1.

51 United Nations Convention on the Rights of Persons with Disabilities, Article 1.





There is no definition of older people accepted at the UN level. However, according to the World Health Organisation, the age of 65 years is accepted in the developed world as a definition of elderly or older person.<sup>52</sup> It should be noted that the likelihood of disability increases with age.<sup>53</sup> Consequently the sub-group of 'very old persons' deserves specific attention.<sup>54</sup>

It is important to recognise that the lines between the four user groups may be blurred in places, with 'children' referring to both those with and without disabilities, or with 'persons with disabilities' also including those above the age of 65, and vice versa.

In many places, family (and family carers) is referred to alongside service users. In the Guidelines, this term is used in a broader sense, including not only parents or spouses but also partners, siblings, children and extended family members.

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52 World Health Organisation, *Definition of an older or elderly person*, [http://www.who.int/healthinfo/survey/ageing\\_defnolder/en/index.html](http://www.who.int/healthinfo/survey/ageing_defnolder/en/index.html)

53 Davis, R. (2005) *Promising Practices in Community-based Social Services in CEE/CIS/Baltics: A Framework for Analysis*, USAID, p.15.

54 *Ibid.*, p.15.







## IV. Moving from institutional care to community-based services

### CHAPTER 1: MAKING THE CASE FOR DEVELOPING COMMUNITY-BASED ALTERNATIVES TO INSTITUTIONS

*This chapter outlines support for the transition from institutional care to community-based services at the European and international level. It covers human rights and values, political commitments and scientific and economic evidence. The purpose of this chapter is to provide governments with evidence of why deinstitutionalisation is the right thing to do and how it can benefit not just the people concerned, but the whole of society. Governments and other stakeholders can draw on this evidence to build up a case for transition, developing collective ownership based on their specific national context.*

#### Obligations under the UN Convention on the Rights of Persons with Disabilities (CRPD)

Article 19 of the CRPD sets out the right of people with disabilities to “live in the community with choices equal to others” and requires that states develop “a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community”.

<sup>55</sup> Children with disabilities must have access to all human rights and fundamental freedoms “on an equal basis with other children”.<sup>56</sup> In order to implement these rights, State Parties must “adopt all appropriate legislative, administrative and other measures” and to “refrain from engaging in any act of practice that is inconsistent with the present Convention”.<sup>57</sup>

55 United Nations Convention on the Rights of Persons with Disabilities, Article 19.

56 *Ibid.*, Article 7.

57 United Nations Convention on the Rights of Persons with Disabilities, Article 4 (General obligations).



### Obligations under the UN Convention on the Rights of the Child

Article 18 obliges member states to ensure that parents have appropriate assistance in their parenting duties and develop services accordingly. Where the parents are unable to provide adequate care the child has a right to substitute family care.<sup>58</sup>

### Obligations under the European Convention on Human Rights

Article 8 guarantees everyone the right to respect for his private and family life, his home and his correspondence and any interference must be both necessary and proportionate.

## 1. Prevalence of institutional care in Europe

### 1.1 People with disabilities and people with mental health problems

A major study<sup>59</sup> funded by the European Commission found that there are nearly 1.2 million people with disabilities living in institutions in 25 European countries.<sup>60</sup> The largest client group reported were people with intellectual disabilities; the next largest group was a combination of people with intellectual disabilities and people with mental health problems. Because comprehensive national data was very difficult to obtain, this number should be taken as simply an indication of the total number of people in institutional care.

### 1.2 Children

A Eurochild national survey<sup>61</sup> highlighted the lack of consistent and comparable data for children in alternative care in Europe. One of the reasons for this is the use of different definitions of types of alternative care. Residential settings can include:

- boarding schools;
- special schools;
- infant homes;
- homes for children with intellectual or physical disabilities;
- homes for children with behavioural problems;
- institutions for young offenders; and
- after-care homes.

<sup>58</sup> Article 20.

<sup>59</sup> *DECLOC Report*, p.27.

<sup>60</sup> EU Member States and Turkey.

<sup>61</sup> Eurochild, *Children in Alternative Care*, National Surveys, January 2010, 2nd edition.



Nevertheless, the survey estimates that there are approximately 1 million children in state/public care in 30 European countries.

Additional (though limited data) is also available from other sources. A World Health Organisation (WHO) survey of 33 European countries found that there are 23,099 children under the age of three in residential care. While on average this represents 11 children in every 10,000, in some countries that ratio was much higher, with between 31 and 60 children under three in residential care. Only four countries included in the survey had a policy of providing foster care rather than institutional care for all children under five taken into care. The estimate for the wider WHO European and Central Asian region (47 out of 52 countries) is that there are 43,842 children under the age of three in residential care homes without parents.<sup>62</sup>

While the number of children in institutional care in Eastern Europe and the former Soviet Union (CEE/CIS region) is said to be decreasing, UNICEF has warned that when the decline in birth rate is taken into account, the proportion of children in institutions is actually higher.<sup>63</sup> It highlighted that particularly children with actual or perceived disability “face a higher risk than others of being institutionalised and of staying so for long periods, many of them for their entire lives”.<sup>64</sup>

### 1.3 Older people

To the authors’ knowledge, no comprehensive data is available for the number of older people in institutional care in Europe or globally. The proportion of people older than 65 receiving residential care in the European Union is on average 3.3 per cent. With 9.3 per cent, Iceland has the highest proportion of persons (65 and over) receiving long-term residential care. The United Nations Economic Commission for Europe (UNECE) estimates that the Nordic European countries provide support to the highest proportion of “frail older persons”, based on a model of decentralised, publicly-provided home care services. Norway, Finland, Sweden and Switzerland report proportions of residential care users between 5 and 7 per cent. In all UNECE countries for which data are available, the share of beneficiaries of residential long-term care is much lower than that of home care.<sup>65</sup>

Research in the CEE/CIS region has shown that older people have traditionally relied on family support, which has diminished following the breakup of the Soviet Union. As a consequence, and also because of falling pension rates, many older people have been left without income or support. This has led to an increase in the number of older people being institutionalised.<sup>66</sup>

In terms of people with disabilities, a major European study highlighted that the likelihood of being placed in institutional care increases with age. This explains why in some countries, where such disaggregated data exists, there are a higher number of women in institutions than men (given that more women live longer than men).<sup>67</sup> This statistic highlights a major challenge in the provision of support: as more people with complex needs survive into old age, additional services are required to meet their needs. This, coupled with the increased longevity of the general population and the onset of dementia and other disabling conditions, places significant pressure on the national, regional and local authorities, the social services and health care sectors.

62 Browne, K. *op. cit.*, pp.3–4.

63 UNICEF *op. cit.* (2010), p.5.

64 *ibid.*, p.27.

65 UNECE Policy Brief on Ageing, No. 7, November 2010, “Towards community long-term care” referring to Huber, M.; Rodrigues, R.; Hoffmann, F.; et al. (2009) *Facts and Figures on Long-Term Care. Europe and North America*. Vienna: European Centre for Social Welfare Policy and Research.

66 Davis, R. *op. cit.*, pp.15–16.

67 Townsley, R. et al. *op. cit.*, p.25.



## CASE STUDY 1: PREVALENCE OF INSTITUTIONAL CARE IN EUROPE

While all policy papers underline that care at home is preferable to residential care, very few incentives have achieved the required increase in public spending on integrated community care, on greater coordination between health and social care and on a further reduction of residential care for older people. With the exception of Denmark, where the construction of care homes was banned by law at the end of the 1980s, all EU Member States spend the bulk of their long-term care budgets on residential care. While much progress has been made in enabling residential homes to become more user-oriented by adapting care and assistance to the individual resident and their needs, some countries are still building large care homes for more than 250 residents. The Danish example shows that it can take several decades to transform the structure of provision, as many care homes built before 1985 have still not been transformed.<sup>68</sup>

## 2. Political commitment to the development of community-based alternatives to institutional care

### 2.1 European legal and policy framework

There is a broad political commitment, at the European and international level, for transition from institutional to community-based care for all user groups. This section highlights the key standards agreed at European and international levels which require countries to develop community-based services as alternatives to institutional care.

#### 2.1.1 European Union

Table 1: Political commitment at European Union level

Document	Relevance to the Guidelines	User group
<b>Charter of Fundamental Rights of the European Union</b>	Sets out the right to live independently for people with disabilities (Article 26) and older people (Article 25), and the need to act in the best interests of the child in all actions relating to children (Article 24). Rights to participate in the life of the community, as well as social, cultural and occupational integration are also included, given their importance to achieving a life of dignity and independence. <sup>69</sup>	All user groups

68 Wiener Krankenanstaltenverbund/KAV (2011) Geschäftsbericht 2010 inklusive Wiener Spitalskonzept 2030 und Wiener Geriatriekonzept. Wien: [www.kav.at](http://www.kav.at)

69 As the Charter is an integral part of the European Treaties these rights are legally binding upon the EU institutions and violations of these rights can be legally challenged at the European Court of Justice.



Document	Relevance to the Guidelines	User group
<b>Europe 2020 Strategy</b>	<p>One of the goals of this strategy is to reduce the number of people living in poverty and social exclusion in the EU by 20 million. To achieve this target, the European Commission established the European Platform against Poverty and Social Exclusion as one of its flagship initiatives. With poverty among the underlying factors in the placement of children in institutional care in countries in economic transition,<sup>70</sup> the process of developing community-based services must go hand-in-hand with other anti-poverty and social inclusion measures.</p> <p>The Platform and the Europe 2020 governance build on the previously established coordination and mutual learning among the Member States in the form of the Open Method of Coordination on social protection and social inclusion (Social OMC). These EU processes can help raise awareness, monitor progress and facilitate mutual learning through the European Semester, peer reviews and discussions within the Social Protection Committee.</p> <p>The Platform also addresses access to housing. This is of particular relevance to people with disabilities, as the mainstream housing market does not cater to their needs in terms of accessibility. It is also relevant to children, as many families are forced to place their children in institutions due to lack of housing.</p>	All user groups
<b>European Disability Strategy 2010–2020<sup>71</sup></b> <i>(continues on next page)</i>	<p>This Strategy presents a framework for action at the European Union level in support of national activities. Achieving full participation of people with disabilities in society by providing quality community-based services, including personal assistance, is a goal of the strategy. In relation to this, the European Commission plans to support national activities to achieve the transition from institutional to community-based care. This includes:</p> <ul style="list-style-type: none"><li>• the use of Structural Funds and the Rural Development Fund for workforce training;</li><li>• adaptation of social infrastructure,</li><li>• development of personal assistance funding schemes,</li><li>• promotion of good working conditions for professional carers; and</li><li>• support for families and informal carers.</li></ul>	<p>People with disabilities (children and adults)</p> <p>People with mental health problems</p>

70 Browne, K. *op. cit.*, p.7.

71 COM(2010) 636 final, p.6.



Document	Relevance to the Guidelines	User group
<i>(continued from previous page)</i> <b>European Disability Strategy 2010–2020<sup>71</sup></b>	The Strategy also intends to raise awareness of the situation of people with disabilities in residential institutions, in particular children and older people  In addition to the Disability Strategy, the EU has a Pact on Mental Health and Well-being <sup>72</sup> and is in the process of developing a Joint Action on Mental Health and Well-being, which will include the evolution of community-based services and socially-inclusive mental health approaches as one of its objectives.	People with disabilities (children and adults)  People with mental health problems
<b>Proposed Structural Funds Regulations 2014–2020<sup>73</sup></b>	The proposed Regulations list transition from institutional to community-based care as a thematic priority. They state that in particular the European Regional Development Fund and the European Social Fund should be used to facilitate this process. (The use of Structural Funds is covered in more detail in the accompanying Toolkit to the Guidelines.)	All user groups
<b>European Charter of Rights and Responsibilities of Older People in need of Long-Term Care<sup>74</sup></b>	The Charter was developed by a group of organisations from ten countries, with the support of the European DAPHNE III Programme. Its aim is to set up a common reference framework that can be used across the European Union to promote the wellbeing and dignity of older dependent people. The Charter comes with a guide for carers, long-term care providers, social services and policy makers. It includes suggestions and recommendations as to how the Charter can be implemented.	Older people

### 2.1.2 Council of Europe

At the level of the Council of Europe, support for the right to live and participate in the community can be found in the European Social Charter (revised), the Recommendations of the Committee of Ministers and the Resolutions of the Parliamentary Assembly. This right has also been strongly promoted by the Commissioner for Human Rights. In addition, a number of judgments by the European Court of Human Rights condemned the circumstances around the placement of individuals into institutional care.

<sup>72</sup> See [http://ec.europa.eu/health/ph\\_determinants/life\\_style/mental/docs/pact\\_en.pdf](http://ec.europa.eu/health/ph_determinants/life_style/mental/docs/pact_en.pdf)

<sup>73</sup> COM(2011) 615 final/2.

<sup>74</sup> See: [http://www.age-platform.eu/images/stories/Final\\_European\\_Charter.pdf](http://www.age-platform.eu/images/stories/Final_European_Charter.pdf)

**Table 2: Council of Europe support for the right to live and participate in the community**

Document	Relevance to the Guidelines	User group
<b>European Social Charter (revised)</b> <sup>75</sup>	<p>The Revised Charter sets out “the right of persons with disabilities to independence, social integration and participation in the life of the community” and requires parties to develop the necessary measures to achieve this right (Article 15). Rights of the child are set out in Articles 16 and 17, which state the importance of promoting family life and the child’s right to grow up in an “environment which encourages the full development of their personality and of their physical and mental capacities”.</p> <p>The importance of developing community-based services for older people is highlighted in Article 23 of the Revised Charter, which requires parties to put in place the necessary measures “to enable older people to choose their life-style freely and to lead independent lives in familiar surroundings for as long as they wish and are able, by means of the provision of housing suited to their needs and state of health or of adequate support for adapted housing [and] the health care and services necessitated by their state”.</p>	All user groups
<b>Council of Europe Disability Action Plan 2006–2015</b> <sup>76</sup>	<p>Action line No. 8 of the Action Plan calls on the Member States to “ensure a coordinated approach in the provision of community-based quality support services to enable people with disabilities to live in their communities and enhance their quality of life”.</p> <p>The cross-cutting action on Children and Young People with Disabilities requires that responsible authorities carefully assess the needs of children with disabilities and their families “with a view to providing measures of support which enable children to grow up with their families, to be included in the community and local children’s life and activities”. Similarly, the section of the Action Plan focused on the ageing of people with disabilities suggests coordinated action should be taken to enable them “to remain in their community to the greatest extent possible”.</p>	<p>People with disabilities (including children and older people)</p> <p>People with mental health problems</p>
<b>Parliamentary Assembly Resolution on Access to rights for people with disabilities and their full and active participation in society</b>	<p>The Resolution invites member states to “...commit themselves to the process of deinstitutionalisation by reorganising services and reallocating resources from institutions to community-based services”.<sup>77</sup></p>	<p>People with disabilities (children and adults)</p> <p>People with mental health problems</p>

<sup>75</sup> Council of Europe, European Social Charter (Revised), 1996. Implementation reports and collective complaints under the European Social Charter (Revised) are examined by the European Committee of Social Rights and result in recommendations to State Parties to the Charter.

<sup>76</sup> Recommendation Rec(2006)5.

<sup>77</sup> Resolution 1642 (2009), para. 8.1.

Document	Relevance to the Guidelines	User group
<b>Committee of Ministers Recommendation on deinstitutionalisation and community living of children with disabilities</b> <sup>78</sup>	The Recommendation states that countries should no longer place children in institutional care. It lists a number of actions that should be taken to make the transition to community-based care, including development of a “national action plan and a timetable [...] to phase out institutional placements and replace these forms of care with a comprehensive network of community provision. Community-based services should be developed and integrated with other elements of comprehensive programmes to allow children with disabilities to live in the community.”	Children with disabilities
<b>Committee of Ministers Recommendation on the rights of children living in residential institutions</b> <sup>79</sup>	The Recommendation sets out the basic principles for the placement of children in residential care, their rights while in residential care, as well as the guidelines and quality standards which should be taken into account. Among the principles, the Recommendation states that “preventive measures of support for children and families in accordance with their special needs should be provided as far as possible”. Furthermore, “the placement of a child should remain the exception and have as the primary objective the best interests of the child and his or her successful social integration or re-integration as soon as possible”.	Children
<b>Committee of Ministers Recommendation on children’s rights and social services friendly to children and families</b> <sup>80</sup>	The Recommendation addresses “children’s rights in social service planning, delivery and evaluation” and highlights that these should be adapted to their and their families’ needs. It calls on Member States to develop “programmes for de-institutionalisation [...] in coordination with efforts to increase family and community-based care services, especially for children under the age of three and children with disabilities”.	Children
<b>Issue papers of the Council of Europe Human Rights Commissioner</b>	In his issue paper on human rights and disability, the Commissioner recommended that states develop the necessary services in the community, stop new admissions to institutions and “allocate sufficient resources to provide adequate health care, rehabilitation and social services in the community instead”. <sup>81</sup> Indicators for monitoring the implementation of the right to live in the community are set out in the 2012 issue paper on the right of people with disabilities to live independently and be included in the community. <sup>82</sup>	People with disabilities (children and adults)  People with mental health problems

<sup>78</sup> CM/Rec(2010)2, para. 20.

<sup>79</sup> CM/Rec(2005)5.

<sup>80</sup> CM/Rec2011(12).

<sup>81</sup> Commissioner for Human Rights (2008), *Human Rights and Disability: Equal Rights for All*. Strasbourg: Council of Europe, para. 8.7.

<sup>82</sup> Commissioner for Human Rights (2012), *The right of people with disabilities to live independently and be included in the community*. Strasbourg: Council of Europe, pp.29–38.





While the European Court of Human Rights (ECHR) has not so far examined the reasons why a country failed to develop community-based alternatives to institutional care, in a number of cases it has looked at cases in which institutional placements amount to deprivation of liberty under Article 5 of the ECHR. In *Shtukurov v Russia*<sup>83</sup> for example, the Court found that the applicant was detained, considering that he was “confined to hospital for several months, he was not free to leave and his contacts with the world were seriously restricted”. It was irrelevant that his placement into the institution was legal under domestic law.<sup>84</sup>

In *Stanev v. Bulgaria*<sup>85</sup> the Court also found that the applicant was “detained” in a social care institution, in violation of Article 5 of ECHR. In addition, the Court found that he was subjected to degrading treatment in violation of Article 3 of ECHR by being forced to live for more than seven years in unsanitary and unsuitable conditions.<sup>86</sup>

In a different case, *Kutzner v. Germany*,<sup>87</sup> the Court looked at additional support that should be provided to people with disabilities to be able to care for their children. It found that the removal of the children of parents with mild intellectual disabilities violated Article 8 (the right to respect for private and family life) because there were insufficient reasons for such a serious interference with the parents’ family life. Importantly, the Court considered the act of separating children from their parents to be the “most extreme measure”.<sup>88</sup>

The rights contained in Article 8 are not absolute. Interference must be deemed “necessary in a democratic society” or meet one of the other exceptions listed in the Article. Therefore, a decision to remove a child from a family must be justifiable in proportion to the aim pursued.<sup>89</sup> When removing children from their parents, the State is obliged to ensure that measures of intervention are both necessary *and* proportionate; if a child is at risk an intervention may be *necessary*; however the action taken must be *proportionate* to the situation. For example, placing children in institutions solely on social grounds is a violation of the right to family life.<sup>90</sup>

In the case of *Wallova and Walla v. The Czech Republic*, custody of the couple’s five children was awarded to a children’s home on the grounds of unsuitable housing. However, the ECHR noted that though this may be relevant, there was no issue relating to the parents’ ability to bring up the children. The State should have made an effort to support the family rather than taking such a drastic measure.<sup>91</sup>

83 [2008] ECHR 44009/05.

84 Parker, C. & Bulic, I. (2010) *Wasted Time, Wasted Money, Wasted Lives... A Wasted Opportunity? – A Focus Report on how the current use of Structural Funds perpetuates the social exclusion of disabled people in Central and Eastern Europe by failing to support the transition from institutional care to community-based services*. London: European Coalition for Community Living, p.46. Hereafter, “*Wasted Lives Report*”.

85 [2012] ECHR 36760/06.

86 Mental Disability Advocacy Centre (2012) *Europe’s highest human rights court issues landmark disability rights ruling*, available at: [http://www.mdac.info/17/01/2012/Europe\\_s\\_highest\\_human\\_rights\\_court\\_issues\\_landmark\\_disability\\_rights\\_ruling](http://www.mdac.info/17/01/2012/Europe_s_highest_human_rights_court_issues_landmark_disability_rights_ruling)

87 [2002] ECHR 46544/99.

88 *Wasted Lives Report*, p.47.

89 *Havelka and others v. Czech Republic* [2007] ECHR 23499/06.

90 *Wallova and Walla v. The Czech Republic* [2006] ECHR 23848/04.

91 *Ibid.*



## 2.2 International legal and policy framework

Table 3: International legal and policy framework

Document	Relevance to the Guidelines	User group
<b>UN Convention on the Rights of Persons with Disabilities</b>	Article 19 sets out the right of people with disabilities to “live in the community with choices equal to others” and requires that states develop “a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”. <sup>92</sup> Children with disabilities must have access to all human rights and fundamental freedoms “on an equal basis with other children”. <sup>93</sup>	People with disabilities (children and adults)  People with mental health problems
<b>UN Principles for the protection of persons with mental illness and the improvement of mental health care</b>	The Mental Illness Principles state that every person with a mental illness has the right “to live and work, as far as possible, in the community”.	People with mental health problems
<b>Recommendations of the World Health Organisation (WHO)</b>	WHO has called for a continued shift away from the use of psychiatric hospitals and long-stay institutions to the provision of community care. It argued that community-based care produces better outcomes when it comes to quality of life, that it better respects human rights and that it is more cost-effective than institutionalisation. The WHO also highlighted the importance of links to housing and employment sectors. <sup>94</sup>	People with mental health problems
<b>UN Convention on the Rights of the Child</b> (continues on next page)	The Preamble states that “for the full and harmonious development of his or her personality” the child should “grow up in a family environment, in an atmosphere of happiness, love and understanding”. In addition, it outlines a range of children’s rights which, taken together, suggest that most children should live with and be cared for by their birth families (Articles 9 and 7). It is the primary responsibility of parents to raise their children and it is the responsibility of the state to support parents in order that they can fulfil that responsibility (Article 18). Children have the right to protection from harm and abuse (Article 19), to an education (Article 28) and to adequate healthcare	Children

<sup>92</sup> United Nations Convention on the Rights of Persons with Disabilities, Article 19.

<sup>93</sup> United Nations Convention on the Rights of Persons with Disabilities, Article 7.

<sup>94</sup> McDaid, D. & Thornicroft, G. (2005), *Policy brief, Mental health II, Balancing institutional and community-based care*, World Health Organisation. Quoting WHO World Health Report 2001, p.1.



Document	Relevance to the Guidelines	User group
<i>(continued from previous page)</i> <b>UN Convention on the Rights of the Child</b>	(Article 24) but they simultaneously have the right to be raised by their family. 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). <sup>95</sup> 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).	Children
<b>UN Guidelines for the Alternative Care of Children</b>	<p>The Guidelines require that in countries where there still are institutions, “alternatives should be developed in the context of an overall deinstitutionalisation strategy, with precise goals and objectives, which will allow for their progressive elimination.”<sup>96</sup> They add that any decisions to establish new institutions should take full account of the deinstitutionalisation objective and strategy.</p> <p>The Guidelines also highlight that the removal of the children from the family “should be seen as a measure of last resort and should, whenever possible, be temporary and for the shortest possible duration.”<sup>97</sup> When it comes to young children, especially those under the age of three, alternative care should be provided in family-based settings. Exceptions to this principle should be permitted only in case of emergency or “for a predetermined and very limited duration, with planned family reintegration or other appropriate long-term care solution as its outcome.”<sup>98</sup></p>	Children
<b>Recommendations of the Committee on the Rights of the Child</b> <i>(continues on next page)</i>	The Committee has encouraged states to “invest in and support forms of alternative care that can ensure security, continuity of care and affection, and the opportunity for young children to form long-term attachments based on mutual trust and respect, for example through fostering, adoption and support for members of extended families.” <sup>99</sup> The Committee has also urged states to set up programmes for deinstitutionalisation of children with disabilities, phasing out institutional placements and replacing these forms of care with “a comprehensive network of community provision”. <sup>100</sup>	Children

95 Mulheir, G. & Browne, K. *op. cit.*

96 United Nations *op. cit.* (2009), para. 23.

97 *Ibid.*, para. 14.

98 *Ibid.*, para. 22.

99 OHCHR *op. cit.*, p.38.

100 *Ibid.*, p.39.



Document	Relevance to the Guidelines	User group
<i>(continued from previous page)</i> <b>Recommendations of the Committee on the Rights of the Child</b>	In terms of prevention, the Committee has clarified that “children with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects”. Examples of family support services highlighted by the Committee include the “education of parent/s and siblings, not only on the disability and its causes but also on each child’s unique physical and mental requirements; psychological support that is sensitive to the stress and difficulties imposed on families of children with disabilities; material support in the form of special allowances as well as consumable supplies and necessary equipment [...] necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community”. <sup>101</sup>	Children
<b>WHO European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families</b> <sup>102</sup>	The Declaration highlights the negative impact of residential institutions on the health and development on children and young people, and calls for the replacement of institutions with high-quality community support.	Children with disabilities
<b>Recommendations of the Committee on Economic, Social and Cultural Rights</b>	<p>In a General Comment, the Committee states that “national policies should help older people to continue to live in their own homes as long as possible, through the restoration, development and improvement of homes and their adaptation to the ability of those persons to gain access to and use them.”<sup>103</sup></p> <p>Housing rights are seen as an integral part of economic, social and cultural rights within the international human rights instruments. The Committee on Economic, Social and Cultural Rights and the European Committee on Social Rights have established the concepts of minimum core obligations and progressive realisation of rights according to available resources in the context of the right to an adequate standard of living.<sup>104</sup></p>	Older people All user groups

101 United Nations Committee on the Rights of the Child, *General Comment No. 9 – The rights of children with disabilities*, 2006, para. 41.

102 World Health Organisation (2010) *European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families*, para. 10.3.

103 OHCHR *op. cit.*, p.38.

104 Commissioner for Human Rights (2008a) *Housing Rights: The Duty to Ensure Housing for All*. Strasbourg: Council of Europe, p.3.

Document	Relevance to the Guidelines	User group
<b>UN Principles for Older Persons (the Madrid Declaration)<sup>105</sup> and the UN General Recommendation on Older Women and Protection of their Human Rights<sup>106</sup></b>	Both documents support the fundamental right of all people to remain integrated in and participate in society, calling for actions to support older people's independence and autonomy and for services "to assist people to reach their optimum level of function".	Older people
<b>Regional Implementation of the International Action Plan on Ageing – the UNECE Strategy<sup>107</sup></b>	Based on the Madrid Declaration, the Economic Commission for Europe of the United Nations (UNECE) developed a Regional Implementation Strategy with ten commitments, including "to ensure full integration and participation of older persons in society" and "to strive to ensure quality of life at all ages and maintain independent living including health and well-being".	Older people

### 3. Human rights violations in institutional care

#### 3.1 Neglect, harm and death of children and adults

##### CASE STUDY 2: DEATH OF CHILDREN IN INSTITUTIONS

In one European country, a recent investigation conducted by a non-governmental organisation with the Prosecutor's Office revealed that 238 children died in institutional care in a ten-year period. According to the report, 31 children died of starvation through systematic malnutrition, 84 from neglect, 13 due to poor hygiene, six in accidents such as hypothermia, drowning or suffocation, 36 died because they were bedridden and two deaths were caused by violence. It was also found that violence, binding and treatment with harmful drugs were widespread in institutions for children.<sup>108</sup>

Numerous reports have highlighted serious human rights concerns in institutions across Europe and have drawn public attention to the appalling treatment and living conditions endured by children and adults in some institutions. Common factors marking institutional care are the removal of personal possessions, rigid routines that ignore personal preferences or needs and residents having little or no contact with people outside the institution.<sup>109</sup> Children are often moved from one

<sup>105</sup> United Nations Principles for Older Persons, 1991; Political Declaration and Madrid International Plan of Action on Ageing, 2002.

<sup>106</sup> United Nations General Recommendation no. 27 on older women and protection of their human rights.

<sup>107</sup> ECE/AC.23/2002/2/Rev.6.

<sup>108</sup> Bulgarian Helsinki Committee, <http://forsakenchildren.bghelsinki.org/en/>

<sup>109</sup> OHCHR op.cit., Chapter VI, pp.25–37.

institution to another, losing any connection with their parents and siblings. Children from minority groups (such as the Roma) or with a migrant background often lose contact with their mother tongue, identity or religion, making reintegration with the birth family more unlikely. A national audit of social services for children in one EU Member State<sup>110</sup> revealed that as many as 83% of children are not visited monthly by family members.

Other reports have highlighted cases of physical and sexual abuse, the use of cage beds and other physical restraints, the absence of rehabilitative or other therapeutic activities, the overuse of medication and violations of the right to privacy and family life. Some reports have exposed inhumane living conditions, including lack of heating, malnutrition, unhygienic sanitation and otherwise poorly-maintained buildings.<sup>111</sup> The UN's World Study on Violence against Children found that children in institutions were at a significantly higher risk of all forms of abuse than their peers raised in families.<sup>112</sup>

The United Nations Committee on the Rights of the Child raised concerns about the high number of institutionalised children and the poor standard of living and quality of care in institutions in some countries. The Committee also expressed concerns about inadequate education being provided to children in social care institutions.<sup>113</sup>

Lack of access to health care in institutions has been highlighted in a report for the WHO.<sup>114</sup> It explains that this may be due to "physical distance from referral institutions and hospitals, problems providing transport or resistance by the health services" to admit residents of institutions. In the case of institutionalised children, this may result in untreated hydrocephalus, untreated congenital heart disorders, cleft palates and other major health problems.<sup>115</sup>

The Explanatory Note to Rec (2004)10<sup>116</sup> on the protection of human rights and dignity of people with mental health problems raised concerns about the continuing failure to provide adequate care to people in psychiatric institutions, highlighting the absence of "fundamental means necessary to support life (food, warmth, shelter) [...] as a result of which patients have been reported to have died from malnutrition and hypothermia."<sup>117</sup> A FRA report from 2012 on involuntary treatment and involuntary placement into psychiatric facilities of people with mental health problems pointed to the extent to which people with mental health problems in the EU are exposed to this practice. The report revealed the trauma and fear that people may experience.<sup>118</sup>

Additionally, serious concerns about the use of restraints and seclusion on people with disabilities have been expressed by the Special Rapporteur on Torture, who noted that: "Poor conditions in institutions are often coupled with severe forms of restraint and seclusion...". The Special Rapporteur gave examples of children and adults being tied to their beds, cribs or chairs for prolonged periods (including with chains and handcuffs), the use of "cage" or "net beds" and overmedication. The

110 ARK and Hope and Homes for Children (2012), *The Audit of Social Services for Children in Romania*, Executive Summary, April 2012.

111 *Wasted Lives Report*, p.16. The relevant reports are listed on p.75.

112 Pinheiro, P. S. (2006) *World Report on the Violence Against Children*.

113 OHCHR *op. cit.*, Chapter VI, pp.25–37.

114 World Health Organisation (2010a) *Better health, better lives: children and young people with intellectual disabilities and their families. The case for change*. Background paper, p.11.

115 *Ibid.*

116 CM/Rec(2004)10.

117 OHCHR *op. cit.*, Chapter VI, pp.25–37.

118 European Union Agency for Fundamental Rights (2012) *Involuntary placement and involuntary treatment of persons with mental health problems*. Vienna: FRA., p.7.

use of seclusion or solitary confinement was also singled out as a form of control or medical treatment.<sup>119</sup>

CASE STUDY 3: PEOPLE WITH MENTAL HEALTH PROBLEMS ACCOMMODATED WITH FORENSIC PATIENTS

In one EU Member State, people with mental health problems requiring short (three to four days) treatment in a psychiatric hospital are accommodated together with forensic patients, where the latter may, for example, have received a ten-year sentence in the closed section of a psychiatric hospital. While a special forensic department<sup>120</sup> was set up and equipped in one of the cities, it has not opened due to a lack of resources and qualified personnel.<sup>121</sup>

3.2 Human rights standards relevant to persons in institutional care

In its report on the human rights of people in institutions,<sup>122</sup> the UN Office of the High Commissioner for Human Rights (OHCHR) highlighted those rights and standards which are of particular relevance to children, people with disabilities (including those with mental health problems) and older people in formal care settings. They are summarised in Table 4, below.

Table 4: Human rights standards relevant to persons in institutional care

Living conditions	The relevant human rights standards which provide for the right to an adequate standard of living include the Convention on the Rights of the Child (CRC), the Guidelines for Alternative Care, the UN Convention on the Rights of Persons with Disabilities (CRPD) and the CPT Standards.
Respect for personal autonomy, family life and citizenship	The CRC, the CRPD, the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the European Convention on Human Rights (ECHR) etc. set out the right to private and family life, freedom of thought, conscience and religion, respect for the views of the child, right to participate in cultural life, right to marry and found a family, right to participate in political and public life and others.
Provision of health care	ICESCR sets out the right to the “enjoyment of the highest attainable standard of physical and mental health”, adding that “health is a fundamental human right indispensable for the exercise of other human rights”.  Even though there are detailed standards for the provision of health care in prisons, there are no similar standards for institutional care.

119 OHCHR *op. cit.*, Chapter VI, pp.25–37.  
120 According to Mental Health Europe, forensic hospitals – i.e. places where those accused or convicted of a crime are placed on the basis of their presumed or diagnosed mental health problems or disabilities – are not compliant with the provisions of the CRPD.  
121 Information obtained by Mental Health Europe from a researcher in the Slovenian Ombudsman’s Office. See also: <http://www.delo.si/novice/slovenija/forenzicna-psihiatrija-po-lanskem-odprtju-se-sameva.html>  
122 OHCHR *op. cit.*, Chapter VI, pp.25–37.



**Table 4 (continued): Human rights standards relevant to persons in institutional care**

<b>Personnel</b>	The quality of care, or more specifically the quantity and quality of staff, is considered in some non-binding UN and Council of Europe standards relating to children in alternative care, people placed in mental health facilities and older people. The standards deal with the attitude of staff and respect for human rights and the management, recruitment and training of staff.
<b>Confidentiality</b>	Confidentiality of personal and health data and data protection is covered in a number of standards (such as the UN Guidelines on Alternative Care and the Mental Illness Principles – MI Principles), and is also relevant to implementation of the right to private and family life.
<b>Employment</b>	The right to work is set out in ICESCR, CRPD and the European Social Charter. The MI Principles prohibit the use of forced labour and state that ‘patients’ have the same right to remuneration as ‘non-patients’. They also encourage the use of vocational guidance and training to enable patients to secure or retain employment in the community.
<b>Education</b>	A number of human rights treaties, namely ICESCR, CRPD, CRC and ECHR provide for the right to education. The UN Guidelines state that children “should have access to formal, non-formal and vocational education in accordance with their rights, to the maximum extent possible in educational facilities in the local community”.
<b>Restraint and seclusion</b>	Standards concerning persons deprived of their liberty and those receiving mental health care permit the restraint and seclusion of individuals in certain circumstances. These, however, have to be interpreted in the light of the CRPD, which does not allow any form of restraint or forced treatment. The UN Guidelines provide guidance on the use of restraint and other means to control children. The CPT Standards prescribe that seclusion and restraint should only be used in emergency situations and as a ‘last resort’, and even then only under certain conditions.
<b>Complaints and investigations</b>	The need to establish effective complaints procedures and mechanisms to investigate allegations of human rights abuses is highlighted in both international and European human rights instruments, such as ECHR. If a person has died in circumstances which might amount to a breach of Article 2 (the right to life) under the ECHR, an independent investigation capable of leading to the identification and punishment of those responsible must take place.
<b>Aftercare</b>	The CRPD and the European Social Charter (revised) set out the rights relevant to those leaving formal care, such as the right to health, the right to social security and access to housing in order to live independently.





## 4. Damaging effects of institutionalisation

### 4.1 Children in institutional care

*“[The]...sum total of the research establishes a most compelling and urgent humanitarian need for the youngest of children to be spared the adverse impacts of institutionalization. Sensitive developmental periods during which a child needs close nurturing care occur very early in life and span a broad array of functions related to physical, cognitive, emotional and behavioural wellbeing.”<sup>123</sup>*

The negative and sometimes irreversible effects on the healthy development of children have been well-documented and in some cases date back over fifty years.<sup>124</sup> They are summarised in Table 5.<sup>125</sup>

There is some evidence that institutional care, especially in early life, is detrimental to all areas of child development,<sup>126</sup> and that it predisposes children to intellectual, behavioural and social problems later in life.<sup>127</sup> It shows that in children under three, institutionalisation is likely to negatively affect brain functioning during the most critical period of brain development, leaving long-lasting effects on a child’s social and emotional behaviour.<sup>128</sup>

However, not all of these effects are irreversible. Considering children’s ability to recover from the harmful effects of institutionalisation, the argument for deinstitutionalisation becomes even more compelling. A number of studies demonstrate that children raised in birth, adoptive or foster families fare much better than their peers raised in institutions, not only in terms of physical and cognitive development, but also in educational achievements and integration into the community as independent adults.<sup>129</sup>

The evidence therefore suggests that all institutions<sup>130</sup> for children under five (including children with disabilities) should be replaced with other services that prevent separation and support families to care for their children. Once families have been assessed, recruited and trained and once the necessary community-based services are in place, all children under five should be moved to family-based care.<sup>131</sup> The need for medical interventions should not be used to justify 24-hour placement of children (with or without disabilities) in institutional care.<sup>132</sup>

123 UNICEF (2011) *Early Childhood Development, What Parliamentarians need to Know*. Geneva: UNICEF Regional Office for Central and Eastern Europe and the Commonwealth of Independent States, p.41.

124 Browne, K. *op. cit.*, p.11.

125 Information in the table is the summary of Browne.

126 Browne, K. *op. cit.*, p.16.

127 *Ibid.*, p.17.

128 *Ibid.*, p.15.

129 Rutter et al., *op. cit.*; Hodges and Tizard, 1989 quoted in Mulheir, G. & Browne, K. *op. cit.*

130 For a definition, see p.26 of the Guidelines.

131 Browne, K. *op. cit.*, p.18.

132 *Ibid.*, p.19.



**Table 5: Effects of institutionalisation on children**

Area of child's development affected by institutional care	Consequences of institutionalisation on child's health	Characteristics of institutional care
<b>Physical development and motor skills</b>	<p>Physical under-development, with weight, height and head circumference below the norm;</p> <p>Hearing and vision problems which can be caused by poor diet and/or under-stimulation;</p> <p>Motor skill delays and missed developmental milestones; in severe conditions, stereotypical behaviours, such as body rocking and head banging;</p> <p>Poor health and sickness;</p> <p>Physical and intellectual disabilities as a consequence of institutional care.</p>	<p>Institutions tend to provide a clinical environment with highly regimented routines, unfavourable 'care-giver to child' ratios and unresponsive staff who see their roles more related to nursing and physical care than to psychological care;</p> <p>Children tend to spend a significant part of the day in a cot;</p> <p>There is an emphasis on infection control, as a result of which children experience the outside world only on rare occasions, under strict supervision and limited play.</p>
<b>Psychological consequences</b>	<p>Negative social or behavioural consequences, such as problems with anti-social behaviour, social competence, play and peer/sibling interactions;</p> <p>'Quasi-autistic' behaviours such as face guarding and/or stereotypical self-stimulation/ comfort behaviours, such as body rocking or head banging; in some low-quality institutions, young children become socially withdrawn after six months;</p> <p>Attention-seeking behaviour, such as aggressive behaviour or self-harming (which can lead to social isolation of children or use of physical restraints).</p>	<p>Lack of primary care-giver (a mother figure) in institutional care, which is important for normal child development;</p> <p>Poor conditions, deprivation of interaction with others;</p> <p>Unresponsive care-givers;</p> <p>Poor care-giver to child ratios.</p>
<b>Formation of emotional attachments</b>	<p>Indiscriminate friendliness, over-friendliness and/ or uninhibited behaviour, especially in children admitted to institutions before the age of two;</p> <p>Detrimental effect on children's ability to form relationships throughout life;</p> <p>Children who are desperate for adult attention and affection.</p>	<p>The lack of a warm and continuous relationship with a sensitive caregiver, even in apparently 'good quality' institutional care;</p> <p>Limited opportunities to form selective attachments, especially where there are large numbers of children, small numbers of staff and a lack of consistent care through shift work and staff rotation.</p>



Area of child's development affected by institutional care	Consequences of institutionalisation on child's health	Characteristics of institutional care
<b>Intellect and language</b>	Poor cognitive performance and lower IQ scores;  Delay in language acquisition;  Deficits in language skills, such as poor vocabulary, less spontaneous language and early reading performance.	Under-stimulation
<b>Brain development</b>	Suppression of brain development in young children, resulting in neural and behavioural deficits, especially for social interactions and emotions, as well as language.	Lack of interaction with a caregiver who will handle, talk and respond to the very young child in a sensitive and consistent way, repeatedly introducing new stimuli appropriate to their stage of development;  Lack of opportunity to form a specific attachment to a parent figure;  Emphasis on physical care of children and the establishment of routines, with less emphasis on play, social interaction and individual care.

## 4.2 People with disabilities

### CASE STUDY 4: SEXUAL ABUSE OF WOMEN

A recent report in one of the old EU Member States showed that 6% of women with intellectual disabilities have suffered some form of sexual abuse in institutional care, perpetrated by other residents but also by members of staff. The report attributes this high percentage – which equates to the sexual abuse of several thousand women – to a lack of safeguards which would prevent the crimes from happening and to the inability of these women to access help and support.<sup>133</sup>

As stated earlier in this chapter, people in institutions are more vulnerable to physical, sexual and other forms of abuse,<sup>134</sup> which can have long-term psychological and physical effects.

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 lack of respect for one's personal integrity can hamper an individual's emotional and social development. Terms such as 'social deprivation' and 'taught helplessness' were coined to describe the psychological effects of living in an institution.<sup>135</sup> Language and intellectual development are

<sup>133</sup> Inclusion Europe e-include, "Women with Disabilities Abused in German Institutions", available at: <http://www.e-include.eu/en/news/1052-women-with-disabilities-abused-in-german-institutions>

<sup>134</sup> World Health Organisation & World Bank, *World Report on Disability 2011*, p.59.

<sup>135</sup> Grunewald, K. (2003) *Close the Institutions for the Intellectually Disabled. Everyone can live in the open society.*



also shown to be affected and institutionalisation can lead to various mental health problems, including aggressiveness and depression.<sup>136</sup>

The converse is also true. Research shows that living in the community can lead to an increased degree of independence and personal development.<sup>137</sup> A number of studies have examined the changes in adaptive or challenging behaviour associated with transition from institutional to community-based care. The overall finding was that adaptive behaviour was almost always found to improve in community settings and there was a reduction in challenging behaviour. Self-care skills, and to a lesser degree communication skills, academic skills, social skills, community skills and physical development, have been found to improve significantly with the move to community-based care.<sup>138</sup>

### CASE STUDY 5: EMOTIONAL, SOCIAL AND PHYSICAL DEPRIVATION IN A LONG-STAY INSTITUTION

A study which followed the lives of twenty men living in a locked ward in a long-stay institution found that the men's lives were emotionally, socially and physically deprived. Their individual, gender and social identities were not met and their general health and mental healthcare needs were inadequately addressed. The researchers noted: "Over the years the social invisibility of the men had contributed not only to their desocialisation but also to a degree of dehumanisation."<sup>139</sup>

## 5. Better use of resources

It is widely accepted that investment in institutional care represents poor public policy. This is because public funding is going into services that are shown to produce poor outcomes for the people served.<sup>140</sup> Community-based systems of independent and supported living, when properly set up and managed, deliver better outcomes for the people that use them: improved quality of life, better health and the ability to contribute to society. Investment in such services therefore makes better use of taxpayers' money.

In relation to children, investment 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 behaviour 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.<sup>141</sup>

Despite the evidence demonstrating that community-based models of care are not inherently more costly than institutions, once a comparison is made on the basis of comparable needs of residents and comparable quality of care<sup>142</sup>, 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.<sup>143</sup>

<sup>136</sup> *Ibid.*

<sup>137</sup> *Ibid.*

<sup>138</sup> AAMR and other (2004), *Community for All Toolkit*, Resources for Supporting Community Living.

<sup>139</sup> Hubert, J. & Hollins, S. *Men with severe learning disabilities and challenging behaviour in long-stay hospital care*, British Journal of Psychiatry (2006), 188, pp.70-74.

<sup>140</sup> AAMR and other *op. cit.*, p.91.

<sup>141</sup> Eurochild (2012), *DI Myth Buster*.

<sup>142</sup> *DECLOC Report*, p.97.

<sup>143</sup> Townsley, R. et al. *op. cit.*, p.25.



A major comparative report on progress towards community living in the EU found that in nine countries there were increasing levels of expenditure on institutional care.<sup>144</sup> It also showed that some countries are allocating significant funds towards updating or extending existing residential institutions. Some of these renovation projects focus on improving accessibility and care standards of existing institutions, as well as on increasing the capacity of institutions to clear the waiting lists.<sup>145</sup> A European study looking at outcomes and costs of deinstitutionalisation and community living<sup>146</sup> established that in 16 out of 25 countries for which information was available, state funds were being used at least in part to support institutions of more than 100 places. In 21 countries, state funds<sup>147</sup> were being used to support institutions of more than 30 places. In addition, there is ample evidence of European Union funding being used in the same way, to renovate or build new institutions.<sup>148</sup>

Research into the cost of community-based mental health care versus institutional care has shown that the costs remain broadly the same, but the quality of life of service users and their satisfaction with services are improved.<sup>149</sup> Where institutional care has proven to be cheaper, it is because it was under-resourced and therefore significantly contributing to poor outcomes.<sup>150</sup> Countries should carry out similar studies in order to calculate the costs of institutional care and to establish which resources could be redirected to community-based services.

#### CASE STUDY 6: COST-EFFECTIVENESS OF CLOSING INSTITUTIONS

The study 'One of the Neighbours – Evaluating cost-effectiveness in community-based housing'<sup>151</sup> looked at the cost-effectiveness of closing institutions in Finland. It compared the cost of living and services for people with intellectual disabilities in both institutional and community-based settings. In addition, it mapped the qualitative effects of moving on the lives of residents and their family members. The study found that community-based care is approximately 7% more expensive than institutional care. While in community-based settings, the costs of housing and basic care was found to be lower than in institutional care, the total costs of community-based care were increased by the use of services outside the housing service unit. In institutions, these costs were included in the daily fee.

In terms of qualitative information, almost all family members reported a substantial improvement in the residents' quality of life after leaving institutions. Some residents had experienced an improvement in their health, for instance periods of hospital care had decreased, their behaviour had become calmer or the amount of medication reduced. One of the most significant changes had to do with social relationships: interaction between residents and their families, as well as between family members and housing service unit personnel, had become much more active.

The study concluded that the marginally increased cost of community-based care was outweighed by its beneficial outcomes. This indicates that community-based care is, overall, more cost-effective than institutional care.

144 *Ibid.*, p.22.

145 *Ibid.*

146 *DECLOC Report*, p.22.

147 State funding includes local or regional government funding.

148 See for example, *Wasted Lives Report*.

149 McDaid, D. & Thornicroft, G. *op. cit.*, p.10.

150 Power, *op. cit.*, p.22.

151 Sillanpaa, V. (2010), *One of the Neighbours – Evaluating cost-effectiveness in community-based housing*, Finland.



## Further reading

Brick, Yitzhak & Lowenstein, Ariela (eds.) (2011) *“Ageing in Place”, Global Ageing – Issues and Action*, Vol. 7 No. 2; International Federation on Ageing.

Freyhoff, G. et al. (2004) *Included in Society*, Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People.

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

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Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009).

UNICEF (2011) *Early Childhood Development, What Parliamentarians need to Know*. Geneva: UNICEF Regional Office for Central and Eastern Europe and the Commonwealth of Independent States.

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United Nations Economic Commission for Europe (UNECE), Policy Brief No. 7 (November 2010) *Towards community long-term care*.



## CHAPTER 2: ASSESSMENT OF THE SITUATION

*Assessing the situation is central to developing a comprehensive, effective deinstitutionalisation strategy and action plan. 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, the assessment should look more broadly at local contexts, detailing available resources (financial, material and human), as well as 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.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

Article 31 requires States to collect “appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the [...] Convention”. The information should be “disaggregated” and “used to help assess the implementation of State Parties’ obligations” and to “identify and address barriers faced by persons with disabilities in exercising their rights.”

### Obligations under the UN Convention on the Rights of the Child

Article 23 encourages the gathering and exchanging of information in the field of preventative health care. “States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas”.

## 1. System analysis

This section advises on how to analyse different aspects of the current system, including:

- analysis of the social and health care system;
- analysis of the barriers in mainstream services;
- the collection of socio-economic and demographic data; and
- the collection of qualitative information about the reasons for institutionalisation as well as quantitative information about the system of institutional care.

The analysis is divided into two parts:

- Section 1.1 deals with the needs analysis, usually carried out at a national level, to develop a national or regional strategy and action plan(s); and
- Section 1.2 deals with the local level needs and feasibility analysis, in order to implement different parts of the strategy or action plan(s).

## 1.1 National level: needs analysis to develop a national or regional strategy and action plan(s)

### 1.1.1 Social care, health care and educational systems

Social care (including child protection), health care and educational systems play a crucial role in preventing the separation of children from their families and institutionalisation. It is therefore necessary to analyse each of these systems so that existing problems and needs can be identified.

In some countries or regions, a lack of services is a direct barrier to keeping families together. For example, if provision for inclusive education is limited, the only opportunity a disabled child may have to receive an education is at a residential special school. Other issues may be related to the attitudes and prejudices of personnel in the services involved. For example, in some cases the decision of parents to leave their disabled child in a residential institution is more or less directly influenced by professionals, such as medical doctors, nurses, midwives or social workers. Many parents report that they had been advised to leave their child in care and to have another, 'healthy' one.

#### TESTIMONIAL 2: ATTITUDES AND PREJUDICES OF PROFESSIONALS TOWARDS DISABILITY

"To be told that your child is a 'cabbage' and that you will lose all your friends if you don't place them in institutional care is inhuman. To be told this without empathy for your situation reinforces the damage – and it still happens. Fortunately, we have learned to ignore experts."<sup>152</sup>

Other children may be placed into care because of poverty or other reasons, such as belonging to a minority group. The extent to which this is compounded by the way social, health care and educational systems function should be considered as well.

Medical and social care professionals who lack the skills to communicate with people with intellectual disabilities or speech impairments could also lead to an over-focus on medical aspects and referrals to institutional care. The needs of family carers are also often neglected due to the inability of professionals to assist and refer them appropriately.

In addition to the attitudes and skills of personnel, there might be a number of other problems related to the overall functioning of the systems, such as disorganised or absent prevention services, inadequate staffing, and lack of support for the personnel or excessive workload.

<sup>152</sup> Mencap (2001) *No ordinary life*, London: Mencap, p.23.





## CASE STUDY 7: SHARING INFORMATION ABOUT SERVICES AND REFERRING FAMILIES FOR SUPPORT

In Luxembourg, the Assessment and Referral unit of a long-term care insurance organisation hosts information evenings for general practitioners (GPs, i.e. family doctors), paediatricians and other health professionals in order to raise their awareness of existing support services and measures. It also disseminates leaflets. Paediatricians or specialist doctors are involved in informing parents that the child has a disability, referring the family to special services, and in advising them to file an application for long-term care insurance benefits; GPs are responsible for regular medical check-ups during a child's first years so it is therefore essential for these health professionals to be able to take into account family carers' needs and to refer them to relevant services.<sup>153</sup>

### 1.1.2 Barriers to inclusion in mainstream services

A child or an adult can still be isolated even when they are not behind the walls of a residential institution if their participation is limited by an inaccessible physical environment, educational system and transport, poverty, stigma or prejudice. The analysis should seek to identify any barriers which prevent full participation in community life. It should cover all services and facilities available to the general population, including education, transportation, housing, justice and administration, culture, leisure and recreation. This analysis should inform the planning and implementation of measures to make mainstream services accessible to all, in line with the CRPD.

Analysis of the education system, for example, will provide information about the 'barriers to learning and participation'<sup>154</sup> that prevent children's access to school or hinder their full participation. Such barriers might be found not only in the physical environment in the form of inaccessible buildings but also in curricula, learning and teaching approaches or in existing cultures. For example, a child with a visual impairment might encounter a barrier if all learning materials are printed; the availability of the relevant reading software or materials in Braille would remove the barrier. Children from minority or migrant backgrounds might have a different mother tongue than the rest of the pupils and may need additional support to access the curriculum. Attitudes among personnel that the barriers lie in the individual impairment or disability of the student are also a major challenge for inclusive education.

For all user groups, the provision of services such as health, social support, housing, education, culture, leisure and transport is frequently much less satisfactory in rural and remote areas than in towns and cities. Elderly people living in rural areas face the consequences of urbanisation and labour migration which results in villages and farms being progressively emptied of younger people who may otherwise have been able to support them. This can lead to increased loneliness and the social segregation of elderly people.

153 Grundtvig Learning Partnership (2012) *Self-assessment of their needs by family carers: The pathway to support*. Full report. Available at: <http://www.coface-eu.org/en/Projects/Carers-Project/>

154 Booth, T. & Ainscow, M. (2002) *Index for Inclusion: developing learning and participation in schools*, London: Centre for Studies on Inclusive Education.





## CASE STUDY 8: THE WHO 'AGE-FRIENDLY CITIES' INITIATIVE

The WHO 'Age-friendly Cities' initiative was launched in 2006 with the creation of the WHO 'Global Network of Age-friendly Cities'. The programme targets the environmental, social and economic factors that influence the health and wellbeing of older adults and tries to determine key elements of the urban environment that support active and healthy ageing. It has produced a guide which identifies eight aspects of city life that can influence the health and quality of older people. These are:

- outdoor spaces and buildings;
- transportation;
- housing;
- social participation;
- respect and social inclusion;
- civic participation and employment;
- communication and information; and
- community support and health services.<sup>155</sup>

### 1.1.3 Qualitative information about the reasons for institutionalisation

Research shows that only between 6%<sup>156</sup> and 11%<sup>157</sup> of children in institutional care are orphans. Most of the children have families and the reasons for family separation are related to poverty or lack of support services.<sup>158</sup> This means that separation could have been avoided if the necessary support was provided to the families.<sup>159</sup> Similarly, inappropriate housing, an inaccessible environment and the lack of suitable home care services (but also domestic violence, abuse and neglect) may force many people with disabilities and older people to leave their homes and move to a residential institution. Often the support they need in order to avoid institutionalisation is minimal. For example, in the UK 23% of older people move into a nursing home because they cannot manage their medicines.<sup>160</sup> The analysis should therefore seek to provide a better understanding of the problems that people encounter in their daily lives in the community, which may lead to abandonment and/or institutionalisation.

155 World Health Organization, Ageing and Life Course, Family and Community Health, Geneva; [www.who.int/ageing/en](http://www.who.int/ageing/en)

156 Browne, K. & Hamilton-Giachritsis, C., *Mapping the number and characteristics of children under three in institutions across Europe at risk of harm*, University Centre for Forensic and Family Psychology (European Union Daphne Programme, Final Project Report No. 2002/017/C).

157 Mulheir (2012) *Deinstitutionalisation – A Human Rights Priority for Children with Disabilities* Equal Rights Review.

158 Mulheir, G. & Browne, K. *op. cit.*

159 SOS Children's Villages International, has developed an assessment tool for the implementation of the United Nations Guidelines for the Alternative Care of Children which aims to assess the situation of children in alternative care at national or regional level and can be used to support the development of national or regional strategies and action plans for deinstitutionalisation. Available at: <http://www.crin.org/docs/120412-assessment-tool-SOS-CV%20.pdf>

160 Department of Health (2006) *Supporting People with Long Term Conditions to ... Self Care, A Guide to Developing Local Strategies and Good Practice*, available at: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4130868.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4130868.pdf)





### CASE STUDY 9: ESTABLISHING THE REASONS FOR INSTITUTIONALISATION

The importance of listening to parents and people using services is illustrated by one national example, where the majority of children under the age of three who had been separated from their families were recorded as being the children of young single mothers. Consequently, the planned response was to develop homes for young mothers and babies. Analysis of a group of around 200 recent entrants to care was carried out in one of the country's local authorities where the official figures appeared to show the same pattern as the national ones: that is, of young first-time mothers leaving their children. Most of the children entering care were of Roma origin and the study also involved them being interviewed by other Roma mothers trained as researchers. Here, the findings were very different from the official figures: they showed that few children were abandoned by young single mothers; in fact, most were the fourth or fifth child of parents who could not cope financially. The kind of support needed in these circumstances is very different from that indicated by the official statistics and would require different services.<sup>161</sup>

Qualitative information about the reasons for institutionalisation will form part of the analysis of institutional care systems. However, this does not provide an analysis of the problems encountered by an individual and/or their family. For example, administrative categories such as 'disability' or 'illness' provided as reasons for institutionalisation of the child do not show in any detail what difficulties the child and the family were facing and what kind of support would have been required in order to prevent separation of the family.

The collection of detailed information can be achieved through questionnaires and/or interviews with families, children, adults or older people placed in institutions. It is important to ensure that the research instruments are designed appropriately so that they do not stigmatise families. It is essential that the forms are based on the social model of disability (see page 126 for a definition) rather than on an understanding of disability as an individual problem. For this purpose, it is beneficial for families and/or individuals using the services to be involved in the development of the instruments.

### CASE STUDY 10: A SELF-ASSESSMENT GUIDE TO FAMILIES' NEEDS

The French NGO Association des Paralysés de France (APF) published 'The Guide to families' needs', a self-assessment tool aiming at identifying the needs of a family with a child or adult with disabilities.

The development of tools that enable the self-assessment of family carers' needs is a step towards recognising family carers as partners in care. These tools empower family carers to identify as such and to express their needs. It is easier for them to access information and advice and to make alternative or contingency plans if they are not willing or able to provide care. Self-assessment also promotes greater collaboration between service providers and family carers and supports the development of family carer training programmes.<sup>162</sup>

161 Extract from Bilson, A. & Harwin, J. (2003) *Changing minds, policies and lives: Improving Protection of Children in Eastern Europe and Central Asia. Gatekeeping Services for Vulnerable Children and Families*. UNICEF & World Bank, p.46.

162 Grundvig Learning Partnership, *op. cit.*





## 1.2 Local level needs and feasibility analysis: quantitative and qualitative information about the system of institutional care

### 1.2.1 Definition of 'an institution'

Before collecting information, it is important to formulate and agree a clear definition of 'an institution'. These Guidelines refrain from providing a size-related definition, acknowledging that the size is not the most important characteristic of institutions; rather, it is about how institutions affect the quality of life and dignity of users. However for the purpose of the situation analysis, each country may develop its own context-appropriate definition which specifies the size of the setting. What is important is to make sure that all the main stakeholders (including user-led organisations, groups of parents, carers and service providers) are involved in the discussions on the definition.

### 1.2.2 Information about the residents and institutions

Applying the definition of 'institution', the analysis of the system of residential settings should provide quantitative information about the size of the institutions and the people currently living there.

- **Sample information about each resident**
  - Age
  - Gender
  - Ethnicity
  - Religion
  - Education
  - Where the person was before the placement in the institution, e.g. birth family, maternity hospital, long term residential institution, etc.
  - Family links – whether the person has family members and/or other relatives and whether they are in touch
  - Length of stay in institutional care
  - Reasons for placement
  - Disability/illness/degree of frailty
  - Financial dependency (poverty)
- **Sample information about institutions**
  - Number of institutions by type, e.g. for children of a specific age who are deprived of parental care, institutions for adults with mental health problems, etc.
  - Location of the institution, e.g. in village/town, size of the town in terms of population, etc.
  - Size of institution, including the number of places and number of residents
  - Physical conditions, e.g. the general condition of the building, condition of the sanitary facilities, of the heating system, etc.
  - Number of admissions and discharges
  - Average length of stay in the institutions
  - Personnel information, e.g. numbers, ratio of personnel to users, professions, name of director of the institution



- *Managing authority (ministry, municipality, region, NGO, etc.)*
- *Budget and sources of funding*
- *Services provided*

The above information will be used in the development of the strategy and action plan to support the deinstitutionalisation of the people currently in institutional care. It might also be useful for the development of preventive measures and services. For example, if the analysis of the source of admission shows that a large number of children come from a local maternity hospital, this indicates the need for a service to be based there and a decision may be made to attach a social worker to the ward.

### 1.2.3 Socio-economic and demographic data

Policy-makers planning for the transition to community-based care and support also need to be aware of the wider socio-economic and demographic trends in the population, at whatever level the reform is undertaken. Quantitative data might be gathered on:

- poverty and social exclusion – in line with the Europe 2020 process for EU Member States;
- the numbers of recipients of various social benefits, e.g. relating to disability, pension, housing costs etc.;
- child poverty;
- educational attainment – in line with the Europe 2020 process for EU Member States;
- long-term unemployment;
- the age structure of the population; and
- the ethnic structure of the population.

These data can be very important in identifying the needs of the population. For example, if a region has a large older population, it could anticipate the level of care required to address this and develop community-based services accordingly.

In addition, more specific data could be gathered about those issues that are most likely to lead to institutionalisation, notably rates of psycho-social disability<sup>163</sup> and mental health conditions, physical disability and intellectual disability in the population. Such data can be gathered from the institutions that are due to close, as well as the education, health and welfare benefit systems. Qualitative data should also be gathered through surveys about the sort of care and support people would like to receive. This information should then inform decisions taken by competent authorities regarding the development of community-based services.

The types of data mentioned here are examples and the lists are by no means exhaustive. The basic principle is that the population's needs must be identified in order to develop the right systems of care and support to meet them.<sup>164</sup>

163 An admittedly broad term currently used by the global community (for example, the World Network of Users, Ex-Users and Survivors of Psychiatry used this term throughout negotiations on the United Nations Convention on the Rights of Persons with Disabilities). The term is meant to include people who have been diagnosed, labelled or perceived as having a mental illness, and can include people with personality disorders. People with psycho-social disabilities are sometimes referred to as users of mental health services, having a 'mental illness' or 'mental disorder.' Source: Mental Disability Advocacy Centre, [www.mdac.info](http://www.mdac.info)

164 See also European Social Network (2011) *Developing Community Care*, Part III.1 'Strategic area needs assessment and planning'. Brighton: ESN. Available at: <http://www.esn-eu.org/e-news12-march29-dcc-report>



## 2. Assessment of resources

The needs analysis should be complemented by an assessment of the available resources. Knowing the resources that are already available, or that will become available when the deinstitutionalisation process is complete, will help inform decisions on the use of these resources in community care and any additional resources required.

The assessment of resources should involve the following:

### 2.1 Assessment of human resources

This assessment provides information about the human resources within the system of residential institutions and within the child protection, social care, health and education systems, e.g. number of employees, their qualifications, knowledge and skills. Many of the people working in residential institutions might be employed in the new services or involved in the reformed system in other ways. Social workers could participate in the collection of information about needs in the community or in an awareness-raising campaign. People working in mainstream services, for example teachers with experience in working with disabled children, could also be a valuable resource at a later stage. Other people, who may be outside of the formal care systems could also be part of the process if they possess the relevant knowledge and skills and support the development of community-based services and inclusive society. These might include activists and experts from NGOs or local groups, community leaders, volunteers, and others.<sup>165</sup>

### 2.2 Assessment of financial resources

A comprehensive assessment of the costs associated with maintaining residential institutions is needed to ensure the most effective use of resources in the planning of new services. Guarantees should be provided that the money that is released, as the number of people in institutional care decreases, will be used for the development of community care. (For more information on the planning and transfer of financial resources see Chapter 5).

### 2.3 Assessment of material resources

This refers to the assessment of the state-owned<sup>166</sup> land and buildings in which institutions are housed. Depending on location, condition and size, buildings could be rented out or sold to provide income for the community-based services. They should not be used as long-term residential institutions for another group or in any other way that may lead to isolation, exclusion or low-quality care.

In addition, an assessment of the physical resources available in the community should be carried out jointly with the local authorities as part of the feasibility study (see section 1.2 earlier in the chapter) to determine how they could support the inclusion of people in the community.

<sup>165</sup> Mulheir, G. & Browne, K. *op. cit.*

<sup>166</sup> In some countries, a large proportion of the market, in particular in care homes for older people, is owned by the independent sector (for example, the UK and Netherlands).



### 3. Information about the existing community-based services

Before developing new community-based services, it is important to have comprehensive information about the services that already exist in the community. This helps to avoid the risk of running two parallel services when this is not actually needed and contributes to the effective and efficient use of available resources. For example, there may be organisations or groups that already provide certain community-based services which could be used to support people leaving residential care. They may have valuable experience and materials, such as educational materials, easy-read publications, training plans or tools for person-centred planning which could be shared to avoid duplication of efforts. A useful tool at this stage could be the development of a map showing the distribution of services in the country or region. Such mapping should always be accompanied by an assessment of quality, accessibility and other relevant service features. The analysis of services should not focus solely on social and health services. It should also look at existing services in other areas, such as education, employment, leisure, etc. It is important that all the relevant institutions at a local, regional and national level are involved.

- **Sample information about existing community-based services**
  - Type of service, e.g. counselling centre, training centre, family-type setting
  - Profile of the users, e.g. children with learning disabilities age 3–7, frail or elderly people
  - Location and accessibility
  - Capacity, i.e. how many people could be accommodated (for a residential service) or served
  - Resources
  - Ownership, e.g. private or state
  - Funding source, e.g. temporary project-funding, state funding)

#### CASE STUDY 11: TOOLKIT FOR THE STRATEGIC REVIEW OF HEALTH, EDUCATION AND SOCIAL PROTECTION SYSTEMS FOR CHILDREN

Lumos, the international NGO, has devised a toolkit for the strategic review of health, education and social protection systems for children. The toolkit includes:

- a 'stock and flow' analysis tool to gather comprehensive information on admissions to, and discharges from, institutions. This is accompanied by an observation questionnaire about institutional culture;
- a social work case audit tool that gathers quantitative and qualitative information on frontline cases of children and families seeking assistance from social services. This is accompanied by a questionnaire for managers of social service departments;
- a series of questionnaires that assess national legislation and local practice in relation to: child abuse and neglect/emergency protection; substitute family care; residential care; prevention services; juvenile justice; community health care and early intervention; inclusive education; and standards and inspection, among others;
- a training and qualifications tool for all relevant personnel;
- a buildings and land questionnaire about the institution itself; and
- a financial analysis tool to produce projections of running costs for new services, as well as the total cost of the entire process of transition from institutional to community based care.

This toolkit has been implemented in four countries and the strategic reviews have been used to plan (either nationally or regionally) complete deinstitutionalisation. These plans have helped to convince national, regional and local authorities that deinstitutionalisation is feasible and sustainable. It has also been used to assist in applying for funds.



## Further reading

Bilson, A. & Harwin, J. (2003) *Changing minds, policies and lives: Improving Protection of Children in Eastern Europe and Central Asia. Gatekeeping Services for Vulnerable Children and Families*. UNICEF and World Bank.

Glasby, J., Robinson, S. & Allen, K. (2011) *An evaluation of the modernisation of older people's services in Birmingham – final report*. Birmingham, Health Services Management Centre.

Mulheir, G. & Browne, K. (2007) *De-Institutionalising and Transforming Children's Services: A Guide to Good Practice*. Birmingham: University of Birmingham Press.

ARK & Hope and Homes for Children (2012) *The audit of social services for children in Romania*. Executive summary.

## Tools

Better Care Network and UNICEF (2009) *Manual for the measurement of Indicators for children in formal care*. [http://www.unicef.org/protection/Formal\\_Care20Guide20FINAL.pdf](http://www.unicef.org/protection/Formal_Care20Guide20FINAL.pdf)

SOS Children's Villages International (2012) *Assessment tool for the implementation of the UN Guidelines for the Alternative Care of Children*. Austria: SOS Children's Villages International, available at: <http://www.crin.org/docs/120412-assessment-tool-SOS-CV%20.pdf>

Lumos *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](mailto:info@lumos.org.uk)





## CHAPTER 3: DEVELOPING A STRATEGY AND AN ACTION PLAN

*A strategy and action plan for deinstitutionalisation and the development of community-based services should draw on the information collected during the situation assessment (see Chapter 2). They will enable the coordinated and systematic implementation of reforms on national or regional scale.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

Pursuant to Article 4(1) of the CRPD, all State Parties must “ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities”. In order to translate this commitment into reality, they should take concrete action to establish alternatives to institutional care. This involves establishing clear, measurable and time-bound action plans with specific targets for achieving success. It is suggested that national strategies should include, among other: a target date for the closure of the institution(s), a measurable timetable including progress that can be quantified, prohibiting admissions to long-stay institutions and recognition of the need to develop clear standards for all CBS and that such standards will be developed in close collaboration with representative organisations of people with disabilities and their families, etc.<sup>167</sup> These commitments should go hand in hand with measures to increase the capacity of family and community-based care and/or support in order to ensure institutions do not close before appropriate services are in place. The strategies and action plans should also be accompanied by a budget to clarify how the new services will be funded.

## 1. Participants and process

A good strategy and action plan that take into account the needs and aspirations of the people involved and offer a coordinated response across different sectors can only be developed with the broad participation of all stakeholders. Decision makers from all the relevant sectors, including child protection, health, education, culture, leisure, employment, disability, transport and finance, should be involved. ‘Non-state’ actors (the people who will or might use the services) should be included from the very beginning, together with their organisations, families and service providers. The involvement of service providers will help promote existing good practice. At the same time, these stakeholders will ensure that the policy documents reflect the real needs and interests of those who are most affected. However, in many cases the interest of service users and their families may be different. Therefore it is crucial to ensure meaningful inclusion of both parties in the process.

The approach to reform will depend on the country context and will reflect the stakeholders’ vision of how reform should look. It might be unrealistic to expect the deinstitutionalisation strategy to simultaneously address the needs and requirements of all user groups: children, people with disabilities, people with mental health problems and older people. Each country will have to identify the best place to start on the basis of a comprehensive assessment of the situation.

<sup>167</sup> Parker, C. (2011) *A Community for All: Implementing Article 19, A Guide for Monitoring Progress on the Implementation of Article 19 of the Convention on the Rights of Persons with Disabilities*, Open Society Public Health Program, Open Society Foundations, pp.17–18.



It often makes sense to start where there is already some political and/or community will to make the reform happen. For example, in one country a crisis in an institution for adults with disabilities provided the catalyst for a deinstitutionalisation programme for adults. Only later did plans develop for children. In other countries, it has been common to begin with children's services.

## CASE STUDY 12: REGIONAL PLANNING OF SOCIAL SERVICES IN BULGARIA

In the last decade, Bulgarian family- and community-based care and services for children and adults with care and/or support needs have often been developed without a clear national strategy or a plan. This has led to an uneven distribution of services across the country based mainly on the local capacity of each municipality to plan, the available financial resources and their capacity to implement activities. It resulted in potential service users not having equal access to services.

The regional planning of services was introduced in Bulgaria in 2009, initially as a pilot project in three regions and, since 2010, in all 28 regions of the country. Supported by a relevant legal framework, the purpose of this approach to planning is to improve the coordination between the social services at regional level, to contribute to a more even distribution of services and to improve cooperation between stakeholders. Five-year strategies (2011–2016) for the development of community-based services were drafted with the participation of the main State and non-State actors at regional level. The strategies are in line with the government policy on deinstitutionalisation and are based on the specific local context following the assessment of needs and resources. All relevant State and non-State actors took part in this process.

All stakeholders at the local level support this regional approach to planning, though its results are yet to be evaluated.

## 2. Strategy

### 2.1 Overview

The strategy is the political document which provides an overall framework for guiding the reforms in social care and other systems towards:

- the closure of institutions;
- the development of community-based services; and
- inclusive mainstream services.

Depending on the country context, the strategy could be developed at a national or regional level. It will ensure that the reform is implemented in a coordinated, holistic and systematic way.

Undoubtedly, the most important task for the strategy is to keep the person using or needing the services firmly at the centre of the reforms. The problem with many reforms has been that they focus exclusively on transforming services and reallocating funds. This emphasis on the macro level risks losing sight of the needs of the individual person.<sup>168</sup>

<sup>168</sup> Goering, P. et al. (1996) *Review of Best Practices in Mental Health Reform*, Minister of Public Works and Government Services Canada.



#### KEY GUIDANCE 4: COMPONENTS OF THE DEINSTITUTIONALISATION STRATEGY

- Values and principles
- Measures for prevention of institutionalisation and family separation together with measures to support transition from institutional care to family and/or community living
- Measures to improve the functioning of the child-protection, social care, health and education systems
- Measures to improve the capacity of the workforce
- Measures to ensure equal access to universal services, including health, education, housing and transport
- Social inclusion and anti-poverty measures
- Establishment of national level quality standards and a functioning inspection system for service provision
- Awareness-raising activities
- Required changes in the legal framework to support the implementation of the strategy
- Financial arrangements to support the implementation of the strategy

#### CASE STUDY 13: STRATEGY FOR DEINSTITUTIONALISATION OF THE SOCIAL SERVICE SYSTEM AND ALTERNATIVE CHILD CARE IN SLOVAKIA ('THE STRATEGY')<sup>169</sup>

The Strategy is a deliberately brief document. In principle, it is a policy statement which makes the case for deinstitutionalisation, states the latest EU and international policy developments and Slovakia's commitments, as well as the current state of affairs in social services and childcare. The strategy gives examples of good practice, but most of all it focuses on key principles of deinstitutionalisation and sets out the main implementing measures and documents, together with a time frame for their adoption.

The Strategy is further developed in (and should be implemented by) two national action plans ('NAPs'):

1. NAP for the transition from institutional to community-based care in the social service system for 2012–2015.<sup>170</sup>
2. NAP/Concept Paper on the Enforcement of Judicial Decisions in Children's Homes for years 2012–2015, with a view to 2020.<sup>171</sup>

169 Approved by the Government resolution no. 761/2011 of 30 November 2011.

170 Approved by the Ministry of Labour, Social affairs and Family of the Slovak Republic (MoLSAF) on 14<sup>th</sup> December 2011.

171 Plan of transformation and deinstitutionalisation of alternative care of children: approved by Ministry of Labour, Social Affairs and Family of the Slovak Republic on 14<sup>th</sup> December 2011.



## 2.2 Principles

The strategy should formulate a clear vision of the future care system based on the principles and values enshrined in the international human rights documents, such as the CRC, the UN Guidelines for the Alternative Care of Children, the CRPD, the Madrid Declaration and Action Plan on Ageing, the ECHR and any other relevant instruments. Concerning children, this will, for example, involve recognising the principles of *necessity* and *appropriateness*, i.e. the need to ensure that children are not unnecessarily placed in alternative care and that, where out-of-home care is provided, it is provided in appropriate conditions and that it responds to the child's rights, needs and best interests.<sup>172</sup>

The strategy should also, for example, recognise that *all* children should grow up and develop in a family environment, including children with disabilities; that all children have equal rights, therefore children with disabilities have the same rights to family life, education and health as children without disabilities.<sup>173</sup> It will require a shift in the way people with disabilities in general are perceived: from patients and passive objects of care to citizens with equal rights; the promotion of principles of full participation and inclusion in society and of choice, control and independence. It also means that the rights of older people to lead a life of dignity and independence and to participate in social and cultural life should constitute the leading principle in providing care for older people.

## 2.3 Components of the deinstitutionalisation strategy

### 2.3.1 Prevention and the transition to community and independent living

A comprehensive strategy for deinstitutionalisation needs to focus simultaneously on two areas:

**i. measures which seek to prevent institutionalisation and the need for alternative care**

In the case of children this involves providing support and assistance to families and parents in order to prevent separation. For older people, this involves designing policies which will allow them to stay in their own homes for as long as possible and to enjoy their independence.

**ii. measures aimed at bringing back to the community those people who are currently in institutional care and supporting their independent living**

For children, this means that priority is given to reintegration into the birth or extended family, as well as the development of family-based and family-like care options for those children for whom reunification is not appropriate. For people with disabilities, including those with mental health problems and older people, priority should be given to solutions supporting their independent living in the community and in their own homes. Group homes and other similar residential services which combine housing with care should not be seen as the default alternative to traditional institutions (see Chapter 5).

### 2.3.2 Funding

Financial arrangements to support the implementation of the strategy should be specified: what funds are already available, what will become available after the closure of the institutions, what additional funds will be provided and what are their sources (see Chapter 6). A key factor for the success of reform is to make sure that the funds currently used to maintain residential institutions

<sup>172</sup> United Nations Guidelines for the Alternative Care of Children, para. 21.

<sup>173</sup> For further information see Mulheir, *op. cit.*



are protected and transferred to the development of new community-based services ('ring-fencing' the funds). It is also important to ensure the sustainability of financing after implementation of the strategy and the action plan is complete. For many countries, EU Structural Funds will be an important source of funding.

### 2.3.3 Social inclusion

The strategy should express a clear commitment to social inclusion. The closure of institutions and the development of a range of community-based services is only one aspect of this process. Measures should be introduced to make public services, such as health care, education, life and job coaching, housing, transportation and culture, inclusive and accessible to all, regardless of their age or impairment. They should be accompanied by actions aimed at alleviating poverty, which is still one of the main reasons for institutionalisation in many countries. Anti-poverty and social inclusion policies are in line with the Europe 2020 strategy goal to reduce the number of people living in poverty and social exclusion.

### 2.3.4 Quality standards for service provision<sup>174</sup>

The strategy should foresee the establishment of clear standards of service provision set at the national level and subject to inspection. Although services will be planned and delivered at the local and/or regional level, it should be the responsibility of the national government to set common standards. These standards should be linked with the human rights and quality of life of the users rather than focused on technical issues (see Chapter 9). The same standards should apply to all services, whether they are provided by NGOs or for-profit providers, as well as local authority or State-run services. It should be noted that standards must be part of a national system for inspection of the quality of services. Standards are a tool of inspection; without systems to inspect and intervene where standards are not met, improvement in quality is likely to be inconsistent across services.

A public system for the independent review of services and evaluation of quality should be introduced alongside the promotion of in-house quality management systems by service providers. Effective evaluation systems should not only look at what the providers are doing but should seek to identify the outcomes for people using the services.

### 2.3.5 Legal framework

The existing legal framework should be revised and amended to ensure that all hindrances to the successful implementation of the reforms are removed. The legislation should support the full inclusion and participation of different groups in society, in line with the main international and European human rights documents. Together with this, the necessary legal framework for provision, funding and access to services should be in place to ensure the sustainable provision of services (see Chapter 4). Legislative and regulatory reform is often needed to introduce new types of services (such as specialist foster care), or new professions (such as Occupational Therapists), in order to ensure all required community services can be developed.

### 2.3.6 Capacity of the work force

The role of practitioners working in the statutory systems is central to the delivery of the vision for reform. A variety of measures may be considered to increase the professional knowledge and skills of the personnel and to ensure that they have adequate support such as training and supervisions. However, the greatest challenge is to change the culture of the system in order to

<sup>174</sup> Recommendation CM/Rec(2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities.



address and transform existing prejudicial attitudes towards the service users. It should be noted that many personnel are low-paid and untrained. Providing care in institutions, where staff-to-user ratios are insufficient, often results in personnel only fulfilling the bare minimum of physical care for residents. They reap little reward from their work and often become as institutionalised as the residents themselves. Specific actions are required to empower personnel to become positive agents of change, rather than factors of resistance.<sup>175</sup>

### 2.3.7 Capacity of child protection and social care systems

The effective functioning of child protection and social care systems is central to the successful implementation of the reforms. Difficulties should be analysed and appropriate measures implemented to ensure that there is a sufficient number of personnel and good coordination. Efficient mechanisms to prevent the separation of children should also be in place so that families can be referred to appropriate services, avoiding the unnecessary entry of children into alternative care and institutionalisation.<sup>176</sup>

#### KEY GUIDANCE 5: CHILD AND ADULT PROTECTION POLICIES

When conducting reform, a child protection policy which includes provisions on responding to child protection concerns should be developed as part of the reform strategy. The policy should cover the following aspects:

- children at risk of immediate harm;
- allegations made against staff members;
- need for placement of children at risk; and
- emergency intervention (e.g. to prevent severe neglect or abuse).

Together with this, a policy for the protection of vulnerable adults at risk of abuse should be in place in order to ensure immediate and effective response in cases of abuse or risk of abuse.<sup>177</sup>

It should be noted that in this context ‘child protection’ refers strictly to the protection of children from child abuse and neglect (CAN). It should not be confused with the broader term of ‘child protection’ used in some countries to denote systems that look after vulnerable children.

### 2.3.8 Awareness-raising

Awareness-raising activities should accompany the reforms in all areas. Often, negative attitudes and myths about certain groups may hinder the development of community-based options and must be addressed in a timely manner. Together with this, it is important to plan activities to raise the awareness about the support available in the community among people and families who are

<sup>175</sup> Mulheir, G. & Browne, K. *op. cit.* pp.100–103, 107.

<sup>176</sup> UNICEF *op. cit.* (2010).

<sup>177</sup> Department of Health and Home Office (2000) *No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*, Available at [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4074540.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4074540.pdf)



users (or potential users) of services. This is particularly important for families, since family carers themselves are not always aware of their own needs ('hidden carers'<sup>178</sup>). Finally, it is also important to systematically engage and inform the services and authorities in the community which people contact when they are in need, including family doctors, social and welfare services, local authorities and religious organisations. NGOs can also play a crucial role in this.

### 2.3.9 Moratoria

The commitment to *stop building new institutions* is seen as a central precondition for the success of a deinstitutionalisation strategy.<sup>179</sup> Equally important is the need to *stop new admissions* into institutions that are in the process of closure. There may be financial incentives for directors of institutions to fill empty beds or for the local authorities to keep the number of children high in such facilities where higher cost-per-child allocations for children in large-scale institutions exists, and this needs to be addressed. The lack of support services in the community may also put pressure on directors to continue admitting residents even though the institution is earmarked for closure. This, however, carries the risk of delaying the process indefinitely.

With regard to children, moratoria could be introduced as part of measures aimed at reducing the number of children entering institutional care and could be accompanied by actions to create incentives for local authorities to invest in the development of preventive services.<sup>180</sup>

However, it is essential to ensure that a complete moratorium on admissions to institutions is not introduced until such time as there are adequate services established to place children who do require some form of alternative care. Instead the moratorium should be introduced gradually and in parallel with the development of community-based services. In one country where a moratorium was introduced on the admission of babies to institutions, it resulted in an increased number of babies spending long periods of time in maternity or paediatric hospital wards where the conditions were often worse than those in the institutions. This had a negative impact on the health and development of these children.<sup>181</sup>

### 2.3.10 User-led organisations

The important role that user-led organisations play in supporting the inclusion of service users should be recognised in legislation and funding. The services for independent living that many user-led organisations provide, such as peer support, advocacy training, information and advice, should be seen as part of the mix of community-based services funded by the State. In addition, they should be involved in the decision-making process at national, regional and local level. Organisations representing the users of psychiatry/mental health services should participate on an equal footing on all platforms where other organisations of disabled people are consulted.

Sometimes the participation of users and their organisations is done in a 'tokenistic' way to show to the public that they are involved, while in effect they have no or little power to influence decisions. Meaningful user involvement is rooted in the principles of citizenship and democratic participation and should give users more control over the way services are developed and implemented. For people with specific difficulties in understanding and communication, such as young children and people with intellectual disabilities, additional time and resources should be allocated to ensuring their meaningful participation.

178 Grundvig Learning Partnership, *op. cit.*

179 DECLOC Report.

180 Eurochild (2012a) *De-institutionalisation and quality alternative care for children in Europe: Lessons learned the way forward*, Working paper.

181 Mulheir, G. & Browne, K. *op. cit.*





### 2.3.11 Learning sites and pilot projects

It is common for the introduction of new policies or programmes to be accompanied by demonstration projects. These projects serve to show how policies work in practice and serve as learning sites. In the context of deinstitutionalisation, learning sites could be used to gain experience about the development and implementation of innovative services<sup>182</sup> and to develop the capacity to manage larger-scale reform programmes. Below is an example of a demonstration project in the Republic of Moldova.

#### CASE STUDY 14: COMMUNITY FOR ALL MOLDOVA INITIATIVE<sup>183</sup>

*After spending most of his life in a residential institution in Moldova, Ion now 27, moved back to his home village in Oxentea. With the support of the local community Ion is building his own house on his family's land and is growing vegetables in his garden. "I want to dig a well here so that I don't have to carry my water from afar and to rear birds and animals. I need to buy the tools I need to work around the house and in my garden. One needs all kinds of tools around the house. Also I need money to buy all these so I am looking for work in the village, harvesting corn, grapes..."*

##### Scope

The Community for All Moldova initiative (C4A MD) is a demonstration project for the deinstitutionalisation of people with mental disabilities<sup>184</sup> in Moldova.<sup>185</sup> The project aims to transform the residential system of care for people with disabilities in Moldova by piloting the closure of the institution for boys and men with mental disabilities in Orhei and replacing it with a range of community-based services and support. In order to ensure a sustainable shift from institutions to community living, emphasis is also placed on developing policy, legislation and building local capacity for managing deinstitutionalisation projects and the provision of quality community-based care.

##### Background

Moldova's system of care and support for people with disabilities is based predominantly on institutional care. Many people with disabilities, in particular those with mental disabilities, are isolated in large residential institutions or at home with no support. They are excluded from community life with no access to education or employment. In recent years, Moldova has shifted towards the social inclusion of people with disabilities and subsequently adopted a Strategy for the Social Inclusion of Persons with Disabilities and ratified the CRPD. It also initiated the process of reforming the residential care system for children; however children with mental disabilities were not included in this process until the inception of the C4A MD.

The shift in Moldova's policy was not complemented straightaway by measures for practical implementation. When the C4A MD initiative was established at the end of 2008, the legislation and financing mechanisms for welfare and education services provided solely for institutions. The few community-based services operating in the country had been established by NGOs and operated mostly with donor funding. There was very limited capacity, even among NGOs,

<sup>182</sup> DECLOC Report, p.103.

<sup>183</sup> This case study was submitted by Raluca Bunea at the Open Society Mental Health Initiative, Budapest, Hungary.

<sup>184</sup> The Community for All Moldova initiative uses the term 'people with mental disabilities' to refer to people with intellectual disabilities and/or people with mental health problems.

<sup>185</sup> The initiative was established through a partnership between the Open Society Mental Health Initiative (MHI)/ Soros Foundation – Moldova (SFM), the Ministry of Labour, Social Protection and Family, and Keystone Human Services International USA (KHSI) / Keystone Human Services International Moldova Association (KHSIMA).





to support children with moderate and profound disabilities and almost no capacity to work with adults with mental disabilities in the community.

### Outcomes

The implementation of C4A MD initiative has been successful in initiating the shift from institutions to community-based services and in demonstrating that all people with mental disabilities can live in the community when the right support and services are available. It has also been successful in including the community-based system in policy and legislation and advocating for the redirection of funding from institutions to community-based services. While there is still a long way to go before the institution is closed, the successes thus far have accelerated the pace of reform, paving the way for community living and establishing a community-based system of care recognised in policy and legislation.

### Key results

- More than 70 people were deinstitutionalised through family reintegration or placement in foster care, shared/family living arrangements, and community-based housing.
- More than 40 people were prevented from entering the institution and included in services in the community.
- The policy framework was strengthened: the Strategy and Law for the Social Inclusion of People with Disabilities were adopted by the Parliament; the CRPD was ratified.
- Secondary legislation for community-based services was adopted: all the services piloted in the C4A MD are now regulated in secondary legislation and a national mechanism for redirecting funding from residential institutions to community-based services was adopted.
- Many of the services developed are funded from State budgets through local authorities.
- Capacity and resources were developed in mainstream schools to include children with disabilities in several regions of the country.
- Basic community-based supports are available throughout the country through the operation of mobile teams.

The national media regularly features success stories of people with disabilities and their families, helping challenge the stigma related to disability and change attitudes at community level.

### Challenges

The process of deinstitutionalisation has been a complex one. The C4A MD project was initiated in 2008 and in the last four years 110 people have either moved out of Orhei into community living or were prevented from institutionalisation. There are still over 250 people within Orhei and thousands in several other similar institutions in Moldova. In order to make community living a reality for all people with disabilities in Moldova, there needs to be strong and sustained political will and resource commitment to support the complete shift from institutions to a community-based system of care. Continuous investment needs to be made in building skills, knowledge, services, and infrastructure that allow for people with mental disabilities to live and participate in communities as equal citizens.

### Key challenges:

- Complexity of the approach: the need to ensure placement in the community, access to mainstream services, access to specialised services (which need to be created), access to education and employment.

*(continues on next page)*





#### CASE STUDY 14 (continued from previous page)

- Resistance from the institution.
- Limited capacity among service providers (public and NGOs) to provide services to people with mental disabilities.
- Maintaining political will among local governments when there are few incentives and many responsibilities with regard to having community-based services in their jurisdiction.
- Ministry of Finance: rigidity to move towards funding for community-based services; cost efficiency vs. funding for social change approach.
- Engaging other donors, including the European Union, to provide bridge funding to sustain the deinstitutionalisation effort.<sup>186</sup>

### 3. Developing an action plan

Policies for deinstitutionalisation and the development of community-based services too often remain at the level of declarations without practical implementation. In countries where implementation has been successful, the existence of comprehensive short-term and long-term plans has been a crucial factor.<sup>187</sup> Realistic action plans, which accompany the strategy, should be developed with the involvement of all stakeholders.

As it is not likely that any government would have the resources to implement deinstitutionalisation simultaneously for all people currently living in segregated settings, the plan should clarify the group of people (such as children under the age of three or older people) which would be the immediate priority. This should be decided on the basis of the assessment of the situation and in consultation with all stakeholders.

In addition, it is recommended the action plan should comprise at least the following elements:

- composition and role of the management and leadership team;
- activities corresponding to the goals and measures in the strategy;
- time frame;
- responsible institutions and people;
- services that will be developed;
- costs, available resources and funding required; and
- monitoring and evaluation framework.

The incorporation of a monitoring and evaluation framework into the action plan is essential. It will provide ongoing information about the progress of the reform and give an indication of the problems encountered, which should then be addressed in a timely manner before they escalate into crisis. The framework should include: monitoring and evaluation indicators, responsibilities for coordination of the process and timeframe (e.g. at what periods will the plan be reviewed).

<sup>186</sup> For further information see: Videos of success stories <http://www.inclusion.md/ro/videogallery/9> and <http://www.youtube.com/watch?v=sCsZviOCxSE>. For policy and legislation in Russian and Romanian, see <http://www.mpsfc.gov.md/md/hotariri/> and <http://www.mpsfc.gov.md/md/legi/>

<sup>187</sup> Freyhoff, G. et al. *op. cit.*





## KEY GUIDANCE 6: PLANS FOR THE CLOSURE OF INSTITUTIONS

For each institution earmarked for closure, the following plans should also be developed.<sup>188</sup> These plans will help carry out the national action plan at the local level.

- Plans for the preparation/support and transition of users to community living, based on their individual needs and preferences (Chapters 7 and 8).
- Plans for the development of community-based services, which take into account the needs and preferences of the users (Chapter 5).
- Plans for the redeployment and training of personnel, considering individual preferences and the requirements of the new services (Chapters 10 and 9).
- Plan for the alternative use of land and/or the building/s of the institution (Chapter 6).
- Funds and funding sources (Chapter 6).
- Preparation of the local community – e.g. awareness raising and education activities (Chapter 8).

Plans for deinstitutionalisation are often developed “under conditions of maximum ignorance and minimum experience”<sup>189</sup> and therefore it is likely that plans may need to be modified as implementation progresses. This should not be seen as a problem, but rather as a normal part of the process of implementation of activities: monitoring, reviewing and revising the activities based on lessons learned. It is essential however, that reviewing and revising plans does not lead to indefinite postponement and that proposed changes are based on the human rights values and principles and are made in consultation with all the key stakeholders.

## CASE STUDY 15: DEINSTITUTIONALISATION IN THE PSYCHIATRIC FIELD: A PROJECT FOR DEVELOPMENT OF ADULT PSYCHIATRIC SERVICES IN CENTRAL FINLAND (2005–2010)

In 2005, the number of patients in psychiatric hospitals in Central Finland significantly exceeded that of the rest of the country. There were considerable differences between municipalities regarding the use of hospital treatment and the resources available for outpatient care, with no home treatment teams or ‘mobile teams’ in the province. The inadequate open care services had led to the inappropriate use of in-patient care with a lack of good practices.

The goal of the project was to create a comprehensive plan for the development of psychiatric services in Central Finland covering the principles of good practice, the main types of service and models of care, division of responsibilities and gradation of services (primary versus specialist care), structure and resources of the care system, follow-up, evaluation and costs. The plan was to be developed in co-operation with municipalities, health care centres, community mental health teams, psychiatric hospitals and social services.

*(continues on next page)*

188 DECLOC Report, p.55.

189 DECLOC Report, p.57.





### CASE STUDY 15 *(continued from previous page)*

The specific objectives set in 2005 included:

- the development of a centred outpatient care system;
- the establishment of unified standards for outpatient services in the region;
- a versatile open care system (including psychiatric emergency duty teams, mobile teams, home-based care and graduated residential rehabilitation);
- hospital treatment organised in fewer units than before;
- a clear division of responsibilities and cooperation between general services and specialist care;
- evaluation, development and training; and
- the creation of a cost-effective care system.

The most valuable changes arising from the project were:

- the development of a range of community-based services including acute home treatment teams, depression nurses, home-based rehabilitation and a psycho-geriatric consultation team (consultation services given by psychiatric nurses);
- the establishment of centred open care services and Community Mental Health Teams in connection with the Health Care Centres; and
- cooperation between the different units and organisations in the field of psychiatric care.

As a result, the provision of adult psychiatric hospital care went down from three hospitals and 0.95 patients-beds per 1000 inhabitants in 2005 to two hospitals and 0.43 patients-beds per 1000 inhabitants in 2011.

## Further reading

Information about the role of local government in achieving inclusion of people with intellectual disabilities (online resource, available at: <http://www.idea.gov.uk/idk/core/page.do?pagelId=6066096>).

Towell, D. & Beardshaw, V. (1991) *Enabling Community Integration: The Role of Public Authorities in Promoting an Ordinary Life for People with Learning Disabilities in the 1990s*. London: The King's Fund.

## Tools

Parker, C. (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*, Open Society Public Health Program, Open Society Foundations, available at: [http://www.soros.org/sites/default/files/community-for-all-checklist-20111202\\_0.pdf](http://www.soros.org/sites/default/files/community-for-all-checklist-20111202_0.pdf)



## CHAPTER 4: ESTABLISHING THE LEGAL FRAMEWORK FOR COMMUNITY-BASED SERVICES

*Once the decision to replace institutions with family-based and community-based alternatives has been taken, it is important to build legislative support for the inclusion of children, people with disabilities, people with mental health problems and older people in society.*

*During this process, existing legislation and policies should be reviewed. Any obstacles to the provision of quality family-based care and services in the community, as well as obstacles to accessing mainstream services, participation in society and user involvement, should be eliminated. Instead, legislation and policies that support family and community inclusion and participation should be adopted.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

Governments must ensure that their laws and practices are consistent with the CRPD. They must “take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities” (Article 4(1)(b)). One of the first steps in this process should be “a comprehensive review of national legislation and policy”, extending beyond disability legislation.<sup>190</sup>

### Obligations under the UN Convention on the Rights of the Child

The CRC recognises that special arrangements need to be made for children with disabilities to ensure that their rights are respected. The assistance “shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.”<sup>191</sup> Countries must also ensure that children are not separated from their parents against their will, unless this is in the best interest of the child (Article 9). Furthermore, children temporarily or permanent deprived of family care are entitled to special protection and assistance by the State (Article 20) and their placement into care must be reviewed periodically (Article 25). All these provisions should be transposed into national law in order to ensure prevention and quality alternative care services.

<sup>190</sup> Parker, C., *op. cit.*, p.11.





## 1. The right to live in the community

In line with the CRC, the CRPD and other relevant treaties (see Chapter 1), legislation should support the principle that children should grow up in a family environment. It should also support the right of people with disabilities and mental health problems to live independently and be included in the community.

In order to protect the rights of the child, legislation should provide for the following: the right of children to remain in a family environment wherever possible, guidance around the placement and alternative care planning when necessary and additional support for children with disabilities. This support includes the provision of community-based healthcare and inclusive education that make it possible for children to receive adequate health care and education, while remaining with their family and integrated within their community.

If explicitly stated, the right to independent living can ensure that people with disabilities and people with mental health problems receive the required support in the community as a matter of entitlement. This means that it is not at the discretion of national, regional or local authorities to decide whether such support will be provided or not. It also ensures that in times of economic crises, individuals do not lose the support they need as part of austerity measures.

The Office of the High Commissioner for Human Rights recommends that, in line with the CRPD, “legislative frameworks shall include the recognition of the right to access support services required to enable independent living and inclusion in community life, and the guarantee that independent living support should be provided and arranged on the basis of the individual’s own choices and aspirations...”<sup>192</sup>

### CASE STUDY 16: LEGAL PROVISION FOR LIVING ARRANGEMENTS

Sweden is one of the few European countries to have legal provisions on the right to living arrangements and support.

Based on the Law on Special Support and Services for People with Disabilities (LSS),<sup>193</sup> people with disabilities can benefit from one or more of the following services: personal assistance, companion services, contact person (support person), relief services in the home, short-term child-minding of school children over the age of 12, short stay away from home (respite care), group homes for children and adults, daily activities, counselling and other personal support.

The same law provides for the right to a place in a group home, an apartment with special services or another specially adapted apartment for individuals deemed to have large or persistent difficulties in managing daily life.<sup>194</sup>

<sup>191</sup> Article 23.

<sup>192</sup> *Ibid.*, p.17.

<sup>193</sup> Law (1993):387.

<sup>194</sup> European Union Agency for Fundamental Rights (2012a) *Choice and control: The right to independent living, Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*, Vienna: EU FRA.



## 2. Access to mainstream services and facilities

For deinstitutionalisation to be successful, children and adults with care and support needs, who are living or moving into the community from an institution, should have access to mainstream services and facilities.

This includes, for example, access to social housing, education, employment, health care, transport, sports and cultural facilities, childcare facilities and any other services from which the community benefits. Relevant anti-discrimination legislation is therefore necessary to ensure that different groups (such as children placed in alternative care, children and adults with disabilities and older people) are not discriminated against in terms of their ability to access mainstream services and facilities.

Some groups may also face multiple discrimination, for example on grounds of ethnicity or sexual orientation. Adequate anti-discrimination legislation should guarantee that necessary supports will be made available for everyone to enjoy equal access to mainstream services. This could include, for example, teaching assistants ensuring that children with disabilities or children from ethnic or migrant backgrounds can take part in mainstream education, or the provision of technical aids to enable adults with disabilities to be a part of the mainstream workplace. Protection should also extend to family members of service users. For example, parents should not be denied family benefits and support services because they are not married or because they live in a single or a same-sex household.

Local authorities and NGOs providing services to the groups mentioned above should promote the benefits of universally accessible mainstream services. This approach will contribute to developing mutual understanding and acceptance among the groups since, for example, facilities made accessible to people with disabilities will also be of use to older people and parents with small children.

It is equally important that civil and political rights, such as the right to vote, to marry or have children, are not denied to individuals on grounds of disability or age. When building communities for all, countries should strive to eliminate barriers to participation in all aspects of life.

## 3. Legal capacity and guardianship

It is estimated that around one million adults in Europe – mainly people with intellectual disabilities and/or mental health problems – are subject to some form of guardianship, either partial or plenary.<sup>195</sup> Their guardians are either family members or representatives of the State (for example, directors of institutions, other social care personnel or mayors of municipalities). Those under plenary guardianship lose almost all of their civil rights and require a guardian to make legally-effective decisions for them in most areas of life.<sup>196</sup>

There is a close link between guardianship and institutionalisation, 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.<sup>197</sup>

195 A plenary guardian can be appointed if the court makes a finding of complete incapacity of a person. The guardian has the power to exercise the all legal rights and duties on behalf of the person.

196 Council of Europe, Commissioner for Human Rights, *Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities*, CommDH/IssuePaper (2012a)2, para. 2.1.

197 MDAC-Shine (2011) *Out of Sight – Human Rights in Psychiatric Institutions and Social Care Homes in Croatia*, Budapest-Zagreb, available at: [http://www.mdac.info/sites/mdac.info/files/croatiareport2011\\_en.pdf](http://www.mdac.info/sites/mdac.info/files/croatiareport2011_en.pdf)



The fact that those subject to guardianship are unable to make any of the more important decisions in life, such as where, how and with whom they would like to live, makes this system incompatible with the right to live in the community. The placement of individuals in institutional care by their guardians has also been condemned by the European Court of Human Rights, which ruled in a recent case that systems should give more weight to the individual's own decisions.<sup>198</sup>

For children in institutions, guardianship can also present a significant challenge. In some countries, the local authority acts as the legal guardian for the child and is also the body that makes the decision on allocation of local funds for care services. This can result in a conflict of interests, as a result of which children are placed in institutions outside the local authority and funded by central government, rather than the local authority budget. In a number of countries, the role of legal guardian is not sufficiently resourced to ensure that guardians are able to act in the genuine best interests of children.<sup>199</sup>

Review of legal capacity legislation, which should include the abolition of plenary guardianship, should therefore form part of the transition to community-based services. Instead of guardianship, countries should adopt legislation which will allow individuals to be supported in making decisions, in line with Article 12 of the CRPD and the ECHR.

## 4. Involuntary placement and involuntary treatment

Involuntary placement and involuntary treatment are of particular relevance to people with mental health problems, who may be placed in a psychiatric hospital, restrained, forced to take medication or subjected to other medical procedures against their will. Information collected by Mental Health Europe shows that the majority of people with disabilities living in institutions, regardless of the psychiatric diagnosis, receive anti-psychotic drugs, often without their consent.<sup>200</sup>

There is also evidence that other institutions for children and for adults with disabilities make arbitrary use of psychiatric drugs to control behaviour, where there is no psychiatric diagnosis and no regular review of medication.<sup>201</sup>

The European Commission's 2005 Green Paper acknowledged that compulsory placement and treatment 'affect severely' patients' rights and should only be applied as a last resort, where less restrictive alternatives have failed. In addition, countries should ensure that their legal frameworks in this area do not hinder the options of people with mental health problems to live in the community.<sup>202</sup>

198 Stanev v. Bulgaria 36760/06 (2012) ECHR 46, (2012) MHLO 1.

199 Lumos' unpublished research.

200 Information obtained by Mental Health Europe during a field visit in Hungary in 2011.

201 Lumos' unpublished research.

202 European Union Agency for Fundamental Rights, *op. cit.* (2012).





## UN HANDBOOK FOR PARLIAMENTARIANS ON THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND ITS OPTIONAL PROTOCOL AND CONCLUDING OBSERVATIONS OF THE CRPD COMMITTEE

“A State should carefully review its laws and their operation, particularly in areas such as deprivation of liberty of persons with disabilities, including those with intellectual and mental disabilities. For example, States should note the Convention’s requirements on independent living within the community instead of forced institutionalization or forced medical interventions, and should ensure that there are laws and procedures to monitor the operation of this legislation, investigate cases of abuse and impose punitive measures, as necessary (Article 16 (4)).”<sup>203</sup>

Furthermore, in its concluding observations, the Committee on the Rights of Persons with Disabilities recommended that States “review [...] laws that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; repeal provisions that authorize involuntary internment linked to an apparent or diagnosed disability; and adopt measures to ensure that health-care services, including all mental health care services, are based on the informed consent of the person concerned.”<sup>204</sup>

## 5. Provision of community-based services

Alongside the development of community-based services, countries should establish the legal and regulatory framework governing the delivery of, access to and funding for services. This is important in order to ensure that services are sustainable beyond the finalisation of a deinstitutionalisation plan or strategy.

### 5.1 Funding services

A moratorium on the building of new institutions, which can be a part of a national deinstitutionalisation strategy, should involve blocking the use of all public funds for this purpose. This should extend to major renovation projects of existing institutions (with the exception of life-saving interventions), which would make it difficult to justify closing the institution in the short term.

The prohibition of public funding for the building of new institutions should encompass European funding, notably the Structural Funds and the Instrument for Pre-Accession (IPA). Already, the proposed Structural Funds Regulations for 2014–2020 support investments into community-based alternatives to institutional care. This is explained in more detail in the Toolkit that accompanies these Guidelines.

203 United Nations (2007) *From exclusion to equality: Realizing the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, Geneva, <http://www.un.org/disabilities/default.asp?id=242>, p. 70.

204 Concluding observations of the CRPD Committee for Spain, para. 36, available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx>



## 5.2 Local responsibility for the local population

It is important that relevant agencies in a local area are made responsible for providing services to all local residents who need them.<sup>205</sup> Where individuals are moving from one area to another (for example, leaving the institution and moving back to their home town), cooperation between local authorities is crucial. This is to avoid one local authority relinquishing responsibility before another one has taken over, leading to individuals falling through the gaps in service provision.<sup>206</sup>

## 5.3 Supporting service provision by NGOs

While recognising that the provision of community-based services to those who need them is the responsibility of the State, NGOs should be encouraged to provide high-quality services. The State should establish regulations to enable contracting of NGOs to provide services. In countries where high-quality community-based services are severely under-developed, such organisations are often the source of innovative practice and are able to respond well to local needs.

NGOs providing community-based services should not have to rely on types of funding which make it difficult to secure long-term provision, as this can result in the services being suddenly suspended, leaving service users in a very vulnerable position. This can potentially result in their institutionalisation or re-institutionalisation.

At the same time, this must be balanced with the development of State regulation of NGOs in relation to quality assurance, such as certification as a provider of a given service, together with subsequent reporting and inspection. It is recommended that NGO-led services are funded through clear contracts or grant agreements that set out which services will be provided at what cost. This should be achieved on a needs-led basis, identified jointly by the NGO and a public authority, ensuring consistency with the vision for person-centred and community-based services. This should prevent situations where institutional care providers register as NGOs in order to attract donors and to avoid supervision or monitoring.

### TESTIMONIAL 3: SUPPORTING SERVICE PROVISION TO NGOS

“Short-term funding not only makes it difficult for NGOs to guarantee ongoing community support for vulnerable individuals, but also creates an environment where vast amounts of time and energy are channelled into fundraising and accounting to donors, which detracts from time available to deliver the service. Some of the best practice in many sectors comes from NGOs who are able to focus on a particular area and develop into a centre of excellence. Governments need to capitalise on this and create an environment where support and long-term funding is allocated to organisations able to demonstrate quality and outcomes, as this will ultimately benefit service users and support a more rapid deinstitutionalisation strategy. There must be also systems in place to assess the quality of services provided both by the State and NGO providers”.<sup>207</sup>

<sup>205</sup> DECLOC Report, p.101.

<sup>206</sup> Mulheir, G. & Browne, K. *op. cit.*, p.133.

<sup>207</sup> Quote by a member organisation of Eurochild.



## 5.4 Health and Safety Regulations

Health and Safety Regulations, which are often applied in institutions, can be an obstacle to providing services in the community. Such regulations are focused on eliminating risk based on worst-case scenarios, and are applied universally without considering individuals' abilities and support needs. A preferred approach, used in some countries, is to build risk management into person-centred planning. This consists of individuals and, where relevant, their families, identifying risks and developing risk management approaches and backup plans to protect themselves from potential risks.<sup>208</sup>

### Further reading

Council of Europe, Commissioner for Human Rights, *Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities*, CommDH/IssuePaper(2012)2.

Parker, C. (2011), *A Community for All: Implementing Article 19, A Guide for Monitoring Progress on the Implementation of Article 19 of the Convention on the Rights of Persons with Disabilities*, Open Society Public Health Program, Open Society Foundations.

United Nations, *From exclusion to equality: Realizing the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, Geneva 2007.

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208 Power, *op. cit.*, p.33.



## CHAPTER 5: DEVELOPING A RANGE OF SERVICES IN THE COMMUNITY

*This chapter looks at different types of community-based services for families and children as well as for adults and older people. It stresses the need for strategies for the prevention of family separation, for family reintegration and the development of family-based, high-quality options for alternative care. In addition, it highlights the importance of community-based services for independent living and living arrangements that enable users to make choices and have more control over their lives. The involvement of users and families in the development and implementation of these services should be seen as a priority.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

Article 19 of the CRPD sets out measures State Parties must take to ensure people with disabilities are able to “live in the community, with choices equal to others”. These include giving people with disabilities an opportunity to choose where and with whom they would like to live on an equal basis with others, and not obliging them to live in a particular living arrangement. It further includes an obligation to provide people with disabilities with access “to a range of in-home, residential and other community support services, including personal assistance”. It is clear that this excludes institutional care because services provided must support “living and inclusion in community” and prevent “isolation or segregation from the community”. Finally, States should ensure people with disabilities have access to mainstream services which have to be “responsive to their needs”. When considering services that have to be developed, it is important that Article 19 is read in conjunction with other CRPD articles, such as Article 26 (Habilitation and rehabilitation), Article 27 (The right to work on an equal basis with others), Article 24 (Education), Article 25 (Health) etc.

### Obligations under the UN Convention on the Rights of the Child

According to the CRC children have the right, as far as possible, to know and be cared for by their parents (Article 7) and should not be separated from their parents against their will unless in the best interest of the child (Article 9). The State has a duty to provide support to the parents to assist them in their parental responsibilities (Article 18) and if they are unable to look after them, the child has a right to substitute family care (Article 20). Disabled children also have a right to “effective access to and receive education, training, health care services, rehabilitation services, preparation for employment” (Article 23).



## 1. Principles

Before developing services it is important to build a clear vision of the service model and the principles on which it should be based with a view to respecting the rights of all service users. There is a growing international consensus<sup>209</sup> on the following principles for social services, which should be applied regardless of the type of service (including residential services).

### 1.1 Full participation in the community

Services should enable individual users and families to participate in the community on an equal basis with others. Sometimes the principle of community living is understood narrowly as being resident in the community. This may lead to a model of service provision which perpetuates the isolation of users from the community by focusing, for example, on developing residential services (such as 'group homes') as the main alternative to the system of institutional care. Instead, a wide range of services should be developed which will remove barriers to participation and ensure access to mainstream services, thus contributing to social inclusion. For children this would mean being able to go to mainstream kindergartens and schools, to take part in sports activities etc.; for adults, examples include having access to continuing education and meaningful employment opportunities.

### 1.2 Choice and control

This reflects a move away from the view of people using services as 'objects of care' and of professionals as being 'the experts' in their care. It recognises the right of individuals and families to make decisions about their lives and to have control over the support they receive. Children should also be encouraged and supported to express their opinion and preferences – their views should be respected and taken into consideration when making decisions about them. Access to information, advice and advocacy should be provided for people to be able to make informed choices about the support and, if relevant, the treatment they want.

### 1.3 Person-centred and child-centred support

Traditionally, support has been provided in a service-centred way; that is, trying to fit the person into existing service options. Instead, the needs and preferences of the person and the child should be at the centre and the support should be tailored to their individual situation and should offer personal choices. This means that users and families should also be actively involved in the design and the evaluation of services.

### 1.4 Continuity of service delivery

The support should be provided for the duration of the need and amended in accordance with the changing needs and preferences of the users. This is also important for children and young people leaving care who should receive support for as long as needed to prepare for their transition to independence.<sup>210</sup>

209 See for example Social Protection Committee (2010) *A voluntary European quality framework for social services*, SPC/2010/10/8 final; Mansell, J. & Beadle-Brown, J. (2009) "Dispersed or clustered housing for adults with intellectual disability: A systematic review", in *Journal of Intellectual & Developmental Disability*, 34(4):313–323; Carr, S. *op cit*; Health Service Executive *op. cit.*; Power, Andrew *op. cit.*; and *Ad Hoc Expert Group Report*.

210 On care leavers, see the United Nations Guidelines on Alternative Care of Children, paras. 131–136.



## 1.5 Separation of housing and support

The type and level of support individuals receive should not be determined by where they live, but by their needs and requirements. Support should follow the person wherever they live; even high levels of support can be provided in ordinary housing. Separating the provision of housing and support will ensure that individuals will not lose their support should they decide to change their living arrangements, for whatever reason.

## 1.6 Dispersed over campus/cluster-style housing

‘Dispersed housing’ refers to “apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population”.<sup>211</sup> Campus or cluster-style housing is used to describe “provision of a complex of houses on a specialised campus, or homes for people with disabilities (or older people) which are clustered in a specific housing estate or street.”<sup>212</sup> Between the two approaches, dispersed housing has been shown to provide better quality outcomes for its inhabitants. The disadvantages of campus/cluster housing identified include:

- the size of the living unit;
- less home-like setting and furnishings;
- lower staffing ratios;
- greater use of anti-psychotic and anti-depressant medication;
- less choice; and
- smaller social networks.

The exceptions to this are some situations where people choose to live communally in village communities, where these then serve a mixed population of disabled and able-bodied individuals.

# 2. Preventing institutionalisation

## 2.1 The need for prevention and the importance of families

A comprehensive transformation of the care system towards decreasing reliance on institutional and residential care and towards family and community-based services should prioritise the introduction of effective preventive measures. If the root causes for institutionalisation are not properly addressed and if the mechanisms to prevent admissions to institutions are ineffective, the efforts to end the provision of institutional care are likely to be unsuccessful because the places vacated by the people who have left the institutions will be quickly filled in by newcomers.

It should be pointed out that in the context of children’s services, prevention refers not only to measures aimed at reducing the flow of children into residential care but also at avoiding the separation of the child from their family of origin, thus reducing the entry-flow into the formal care in general. The underlying principle is that the family is the most appropriate environment for the survival, protection and development of the child and that parents have the primary responsibility

<sup>211</sup> Health Service Executive, *op. cit.*, p.72.

<sup>212</sup> *Ibid.*



for raising their children.<sup>213</sup> All children, including children with disabilities, are in principle best cared for and nurtured in their own families, provided that families receive adequate support to perform their parental responsibilities.

Prevention strategies (see below) should aim to support individuals and families and avoid blaming them for being poor or stigmatising them because of their origin, non-traditional family structure, customs and ways of life.

It is a matter of great concern that poverty is still a reason for the removal of children from parental care, while the UN Guidelines explicitly advise against this.<sup>214</sup> The decision to remove a child from parental care solely on the basis of considerations regarding the material conditions or the ethnicity of parents is based on the so called 'rescue mentality': the belief that the children are better cared for and have better life chances being brought up away from ('rescued from') their own families<sup>215</sup>, which reflects the existing societal stereotypes and prejudices against people and groups who differ from the majority of the population.

## 2.2 Abuse/neglect in families

The exception to the principle that the family is the most appropriate environment for the child is a situation where a family's actions or lack of action results in risk of serious harm as a result of abuse or neglect. In these cases, an alternative care option might be in the best interest of the child. Indeed, alternative care is sometimes an absolute necessity in order to protect the child. In these situations, the decision about the most appropriate option should be made in consultation with the child (where age and understanding allow) and any placement in residential care should be seen as a last resort and accompanied by an individual care plan. Where possible, efforts should then be made to help the parents rehabilitate, with a view to reunification. Thus, the effort to prevent the separation of children from their parents should involve both support for families and the provision of appropriate care and protection for vulnerable children.<sup>216</sup>

## 2.3 Older people

For older people, the issue of institutionalisation and deinstitutionalisation is, in many cases, very specific, as they normally move into institutions at an increasingly later stage in their lives. Advance care planning and end-of-life-care therefore concern the prevention of institutionalisation, rather than permanent changes in living and caring conditions.

Embedding prevention and rehabilitation within long-term care for older people at a national, systemic level is of utmost importance and is becoming more widely acknowledged amongst EU countries. It refers to "helping older people to stay healthier, more independent and more socially included for longer and to recover all these capacities as fully as possible when they do require hospital treatment".<sup>217</sup> First steps can be recognised in initiatives such as: national awareness-raising events and multidisciplinary preventive and rehabilitative services in community settings.

213 United Nations Convention on the Rights of the Child.

214 United Nations Guidelines for the Alternative Care of Children, para. 14.

215 Fox-Harding (1997) quoted in Bilson, A. & Cox, P. (2007) "Caring about Poverty", *Journal of Children and Poverty*, 13(1):37–55.

216 United Nations Guidelines for the Alternative Care of Children, para. 8.

217 Kümpers, S., Allen, K., Campbell, L., Dieterich, A., Glasby, J., Kagialaris, G., Mastroyiannakis, T., Pokrajac, T., Ruppe, G., Turk, E., van der Veen, R. & Wagner, L. (2010) *Prevention and rehabilitation within long-term care across Europe – European Overview Paper*. Berlin/Vienna: Social Science Research Centre/European Centre for Social Welfare. Policy and Research, p.21. Available at [http://interlinks.euro.centre.org/sites/default/files/WP3\\_Overview\\_FINAL\\_04\\_11.pdf](http://interlinks.euro.centre.org/sites/default/files/WP3_Overview_FINAL_04_11.pdf)



### 3. Prevention strategy measures

In general, an effective prevention strategy should combine a variety of measures in different areas, such as:

- **Universal access:** As a more general preventive measure (primary prevention) universal access should be provided to quality health care, employment, education, housing, information and communication<sup>218</sup>;
- **Reforms in relevant systems:** A comprehensive strategy should also engage with reforms in the health, social care and child protection systems. This is because they can contribute to institutionalisation either by failing to prevent admissions to institutions or by actively promoting institutionalisation as an option (see Chapter 3). Such reforms might include:
  - the introduction of modern social work practices;
  - training and capacity-building activities for the personnel to address stigma and negative attitudes;
  - training to build skills in certain areas of practice; and
  - strengthening the mechanisms that prevent admissions<sup>219</sup> to limit the number of institutional placements while referring children, adults, families and carers to the appropriate services or care arrangements<sup>220</sup>;
- **Community-based services:** In addition, a range of community-based services should be developed to support children, adults, older people and families who are most at-risk.
- **Income support:** Provision of financial and material assistance should also be included as a way to address poverty, which is one of the main reasons for institutionalisation and family separation.
- **Awareness-raising activities:** Awareness-raising activities will promote more widely the principles and actions taken as part of the general reform.

<sup>218</sup> UNICEF *op. cit.* (2010).

<sup>219</sup> Effective gate-keeping requires one body to be responsible for carrying out individual assessments, decision-making and referral to appropriate services, provision or purchasing of services, keeping records and reviewing plans for children. Information systems to monitor and review the decisions and their outcomes need to be in place as well.

<sup>220</sup> For more information on gate-keeping, see UNICEF *op. cit.* (2010) and Bilson & Hardwin (2003) *Gatekeeping services for vulnerable children and adults. A concept paper.*





### KEY GUIDANCE 7: EXAMPLES OF SERVICES THAT PREVENT FAMILY SEPARATION

- **Family planning:** Education in family planning methods can help avoid unwanted pregnancies.
- **Pre-natal care:** Consultations and advice on issues related to the pregnancy (e.g. health care, nutrition, physical activity), basic skills for caring for a newborn; support if an impairment or congenital abnormality is identified prior to birth.
- **Support in maternity wards:** Support provided by a social care or medical professional to the mother in the first days after the birth of the child (e.g. in breastfeeding, building attachment between the mother and her baby, facilitating the creation of supportive environment in the family, assisting with follow-up support), rooming in. Support for parents where a child is born with a disability, including proper advice and referral to other relevant services and support groups.
- **Mother and Baby Units:** Provide temporary accommodation for expectant mothers and to mothers with babies who are at risk of being separated from their child. During the stay mothers receive support with the care of their child, gain parenting and housekeeping skills.
- **Parent and child foster care placements:** Placement of the parent and their baby or young child in a foster home. The foster carers provide parental advice and support in the parenting tasks. Where the mother is very young, the foster parent provides parenting to the mother, recognising that she is also a child with her own needs.

## 4. Developing community-based services

Below are some examples of community-based services that could be developed as part of a comprehensive strategy for prevention of family separation and institutionalisation. They can also support the re-integration and transition back to the community. The list of services is not intended to be exhaustive; each country should develop a range of services relevant to local need.

The development of new services should be based on the analysis of the situation (Chapter 2) and should be linked to the individual assessment and self-assessment (Chapter 7). Users, their support people, families and carers should be actively involved in the development, delivery, monitoring and evaluation of services.

### 4.1 Importance of mainstreaming

The priorities and needs of children and families, people with disabilities, people with mental health problems and older people should be integrated in all policies and measures (mainstreaming).

## KEY GUIDANCE 8: THE CONCEPT OF REASONABLE ACCOMMODATION

Both the UN Convention on the Rights of Persons with Disabilities and the EU Employment Equality Directive<sup>221</sup> introduce the concept of ‘reasonable accommodation’. According to Article 5 of the CRPD (Equality and non-discrimination), “in order to promote equality and eliminate discrimination, State Parties shall take all appropriate steps to ensure that reasonable accommodation is provided”. ‘Reasonable accommodation’ is defined in Article 2 of the CRPD as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden [...] to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.” To ensure that people with disabilities in the EU have access to mainstream employment, employers are required to take actions such as “adapting premises and equipment, patterns of working time, the distribution of tasks or the provision of training or integration resources”. This obligation, however, is not unlimited and is subject to the requirement that the accommodation does not result in a ‘disproportionate burden’ to the employer.

## 4.2 Integration of services

Where services are delivered by different providers (public, private or voluntary), at different levels (local or national) and from different sectors (e.g. housing, health, employment, education) good coordination is crucial. ‘Service integration’ is an umbrella term referring to “a range of approaches or methods for achieving greater co-ordination and effectiveness between different services to achieve better outcomes for service users”.<sup>222</sup> Examples of approaches include: service coordination, cooperation, partnership, collaboration and joint working. It is argued that integrated services benefit the users as they result in better outcomes, especially for people with multiple and complex needs who often have to deal with a variety of agencies and are expected to improve results in tackling social exclusion. In addition, it is suggested that service integration could be cost-effective.

## 4.3 Examples of services in the community

### ALL USER GROUPS

### 4.3.1 Personal assistance

This is one of the most important services for independent living for children and adults with disabilities. For users to have full control over their assistance (that is, to be able to employ and train assistants themselves and to choose when, how and what kind of assistance to receive) the service needs to contain the following three key elements:<sup>223</sup>

- a self-directed needs assessment;
- cash benefits – paid directly to the user to purchase the service from a provider and/or to organise the service him/herself; and
- peer support.

<sup>221</sup> Directive 2000/78/EC.

<sup>222</sup> Munday, B. (2007) *Integrated social services in Europe*. Council of Europe, p.11. Available at [http://www.coe.int/t/dg3/socialpolicies/socialrights/source/Publication\\_Integrated%20social%20services%20in%20Europe%20E%20\(2\).pdf](http://www.coe.int/t/dg3/socialpolicies/socialrights/source/Publication_Integrated%20social%20services%20in%20Europe%20E%20(2).pdf)

<sup>223</sup> Based on Ratzka, A. (2004) *Model Personal Assistance Policy*, Sweden: Independent Living Institute. Available at: <http://www.independentliving.org/docs6/ratzka200410a.pdf>



The funding that the user receives should cover all costs associated with the service and should be provided by one central funding source. All user groups should have access to the service. People with intellectual disabilities and children can receive support from a third person or an organisation with responsibility for employing and managing the work of their assistants.

Personal assistance should not be confused with home help or home-care services (see below), which differ in the level of control given to the service user.

### CASE STUDY 17: THE 'JAG MODEL' – PERSONAL ASSISTANCE WITH SELF-DETERMINATION

In Sweden, after a person is granted funding for a certain number of hours of personal assistance per year by the National Insurance Agency, they can choose to receive the service from the state, a cooperative or an independent agency or to organise it by themselves.

JAG Association is a Swedish non-profit organisation of people with intellectual disabilities which has established a user cooperative to provide personal assistance to members of the association who want it. The user's choice and control over the assistance is ensured through a system of supported decision-making.

Each user has a legal proxy (personal representative) who supports the user in:

- filing for personal assistance and choosing the service provider;
- choosing a service guarantor; and
- ensuring personal assistance is delivered in a way that is respectful of the disabled person, including recognising his or her personal integrity and monitoring the service to ensure that it meets the standards agreed with the disabled person.

In addition, each user has a service guarantor providing support with recruitment and supervision of the assistants and ensuring the standards of safeguarding, quality and continuity of the service received. The service guarantor is responsible for making sure that personnel are always available and, in case of emergency, must be able to provide personal assistance themselves.<sup>224</sup>

### 4.3.2 Housing adaptations

ALL USER GROUPS

Inaccessible housing has a negative impact on the quality of life of children and adults with disabilities and older people, as well as families and carers. Many people with disabilities and older people are forced to leave their home and go to some type of residential setting, either because their home is not accessible, is dangerous or is not suitably adapted to their needs. Research has shown, for example, that the majority of older people prefer to remain in their own homes instead of going to a nursing home or other type of residential setting.<sup>225</sup> Provision of adaptations and repairs to improve the accessibility, the comfort and the safety of the house or apartment has an important role to play in allowing people to remain in their own homes and avoid institutionalisation.

224 For more information, see: JAG, ENIL (2011) *The "JAG model": Personal assistance with self-determination*, JAG Association.

225 Moriarty, J. (2005) *Update for SCIE best practice guide on assessing the mental health needs of older people*. London: King's College London. Available at <http://www.scie.org.uk/publications/guides/guide03/files/research.pdf>



### 4.3.3 Technical aids and assistive technologies

The term ‘assistive technologies’ refers to a variety of products and services that allow or make easier the implementation of certain tasks by the user, or improve his or her safety.<sup>226</sup> Some examples include: augmentative communication devices, reminder systems, speech recognition software and personal emergency response systems. These technologies are most effective when they are in accordance with the preferences of the user and take into consideration the environment in which they are used or installed. Assistive technologies and technical aids such as wheelchairs and crutches are central to community living for people with disabilities, including children with disabilities and older people. Tremendous progress in electronic devices and information systems (smart homes) provide effective support to independent living for those with declining health or increased frailty, preventing falls and self-neglect and empowering older citizens to live and socially engage with maximum autonomy, safety, security and dignity.

### 4.3.4 Peer support/counselling

Peer support or peer counselling assist people with disabilities, young people leaving care or who have started living independently, families at risk or families reunited with their children, to become empowered and self-confident in finding their own way through the cultural or institutional environment. Such support should be provided by non-professionals on equal basis between the counsellor and the client (peers) through sharing of experience and assistance in gaining autonomy and independence. Peer support is crucial for people who used to live in institutional settings who lack the knowledge and skills to negotiate the mainstream environment.

### 4.3.5. Individual level advocacy

Advocacy can be provided by a trained person (volunteer or paid) or an organisation representing or supporting the user’s group, but can also often be undertaken by a friend or relative, another person with a similar experience or by the users themselves (self-advocacy, see Chapter 8). Professional advocacy means “providing a trained person who, on the basis of an understanding of a client’s needs and wishes, will advise, assist and support that client to make a decision or claim an entitlement and who will, if appropriate, go on to negotiate or make a case for them”.<sup>227</sup>

### 4.3.6 Crisis intervention and emergency services

Various activities aimed at supporting an individual or a family to overcome a difficult situation which has a damaging effect on their well-being. Some examples include: individual and family counselling, crisis resolution teams (which provide intensive and rapid support for people living in the community who are experiencing a mental health crisis) and emergency foster care where children at risk of neglect or abuse can be placed on a short term basis.

226 Cowan, D. & Turner-Smith, A. (1999) “The role of assistive technology in alternative models of care for older people.” In *Royal Commission on Long Term Care*, Research Volume 2, Appendix 4, Stationery Office, London, 325–46.

227 Citizen Information Board (2007) *Advocacy guidelines*.



### CASE STUDY 18: EXAMPLE OF A CRISIS PREVENTION SERVICE<sup>228</sup>

The Mental Health Institute for Children and Adults in Greece has established a unit of Psychiatric Treatment in the Patient's Home, which is based on largely the same principles as mobile psychiatric units.

#### Eligible individuals:

- Individuals with mental health problems going through an acute psychiatric crisis
- Individuals with mental health problems returning home after a long or short term hospital stay
- Outpatients, who have never been hospitalised
- Stabilised individuals with mental health problems and mobility problems

The criteria include the need for a sufficiently stable environment in order to share the responsibility of keeping the individual with mental health problems safe at home, in cooperation with the therapeutic team and the service user.

#### This Unit works according to the following model:

- During the first days of the psychiatric crisis, a team stays at the person's home almost all day, trying to establish a strong and trusting relationship with the service user along with providing medication.
- From the very beginning, the team tries to give the service user responsibilities and not let them adopt the role of an ill person.
- As early as possible, the team supports the person in returning back to their job and social life.
- Gradually, and according to the person's needs, the team reduces its presence but provides constant and continuous follow-up support.
- The Institute also offers stable support and mental health training to the families.
- The team supports the person within their workplace and generally in their social environment, and in this way reinforces their support network.
- The Institute applies Community Sensitisation Programmes (mental health training) in relation to psychiatric disorders and organises training for people in key public positions in order to ensure the support of the local community for the rehabilitation and the social inclusion of the service user.

#### 4.3.7 Short breaks

Designed to give children, adults or older people with disabilities and their carers a break from their usual routine or caring role. The service could be provided in various locations, for example in the family's own home, the home of the short break carer, community settings or residential settings. The breaks can have different durations from a few hours to several days.

ALL USER GROUPS

<sup>228</sup> For more information, see: [http://www.ekpse.gr/about\\_eng.html#](http://www.ekpse.gr/about_eng.html#)



#### ALL USER GROUPS

### 4.3.8 Befriending

Support provided by trained volunteers to children, adults, older people, and families, either for an agreed length of time or on an on-going basis. The service offers an opportunity to individuals and families to overcome their isolation and get more fully involved in the community and social life. Matching volunteers and users is considered to be the key to the success of the service. Training and on-going support to volunteers must be provided and appropriate police checks should be made where children or adults are vulnerable.

#### ALL USER GROUPS

### 4.3.9 Home help and home-care services

Home help consists of home visits to assist with household tasks, such as shopping, cleaning, cooking, laundry or minor maintenance. Home-care services include assistance with daily routine tasks such as getting up, dressing, bathing and washing or taking medicines.

#### CHILDREN

### 4.3.10 Early childhood services

For example, mainstream day-care centres for children providing early childhood education and care for children, aiding socialisation and early learning, while giving parents an opportunity to engage in paid work and other activities.

#### CHILDREN

### 4.3.11 Arrangements for children to attend mainstream day-care, kindergartens or schools

Could involve variety of services, such as personal assistance or resource teachers. This may require adaptation of the school environment and the provision of specialised equipment. There may also be a need for a specially adapted curriculum.

#### CHILDREN

### 4.3.12 Out-of-school care and after-school activities

Different services providing care for children before and after school or during holidays, which usually assist children in improving educational outcomes, while enabling parents to take up employment and training opportunities.

#### YOUNG PEOPLE LEAVING CARE/PEOPLE WITH DISABILITIES/PEOPLE WITH MENTAL HEALTH PROBLEMS

### 4.3.13 Employment-related consultations

Support and assistance with looking for work or preparing job applications.

#### PEOPLE WITH MENTAL HEALTH PROBLEMS

### 4.3.14 Fountain House

Fountain House is a self-help programme/model where members work closely together with professionals. In this model, members (of a House) are partners in their own recovery, rather than merely the passive recipients of treatment. They work side-by-side with the personnel to organise and administer every programme. This opportunity to work and the relationships established are then integral to their recovery. The House does not provide individual or group therapy or offer medication.

#### PEOPLE WITH MENTAL HEALTH PROBLEMS

### 4.3.15 Runaway-house

Runaway-house (Weglaufhaus in German) is a place for people who want to get out of 'revolving-door' psychiatry and have decided that they want to live without psychiatric diagnoses and psychiatric drugs. It opens up a space outside or beyond



the (social) psychiatric net that keeps people dependent, a space in which the residents can try to regain control over their lives. Here they can recover, regain their strength, talk about their experiences and develop plans for the future without psychiatric views of illness blocking access to their feelings and their personal and social difficulties.<sup>229</sup>

#### 4.3.16 'Buddy' service

Trained volunteers support people with mental health problems in reintegrating in the community. The person with mental health problems decides whether they need the support of a 'buddy' or not. Support activities include: shopping, cleaning, leisure activities such as going to the cinema, going to a pub or visiting family members. All activities are carried out the way the person with mental health problems decides. The service should be free of charge.

PEOPLE WITH MENTAL  
HEALTH PROBLEMS

#### 4.3.17 Day-care centres for adults and older people

Provide advice, support, meals and some aspects of personal care, as well as social and cultural activities. For older and especially frail people, they may be of considerable advantage as they can be effective in combating loneliness and isolation. Factors which determine how beneficial day-care centres can be include ease of accessibility, affordability, the choice of services to be used and, of course, users' involvement in the planning, implementation and evaluation of services to be offered.

PEOPLE WITH DISABILITIES  
AND OLDER PEOPLE

#### 4.3.18 Meals on wheels

Distribution of meals to older people in their home.

OLDER PEOPLE

#### 4.3.19 Home-nursing

Home visits by nurses or other health personnel to assist with medical care, such as dressing wounds, medication and various forms of therapy.

OLDER PEOPLE

### KEY GUIDANCE 9: ENSURING SPECIALISED SERVICES DO NOT LEAD TO SOCIAL EXCLUSION

Special attention should be given to ensuring that community-based services do not turn into forms of institutional care in the community. This is an issue in some countries, particularly with regard to specialised day-care centres for children with disabilities. In the absence of a variety of family support services and accessible mainstream services, these places can lead to children becoming isolated from the community and from their non-disabled peers. The children have little contact with people or activities in the community and instead of going to school they spend their days in the centre where the care is often limited to medical and physical rehabilitation. The same challenges have been noted in community services for people with mental health problems.

229 For more information, see [http://www.peter-lehmann-publishing.com/articles/others/iris\\_eng.htm](http://www.peter-lehmann-publishing.com/articles/others/iris_eng.htm)





## 5. Living arrangements

Central to the transition from institutional care to life in the community is the provision of suitable living arrangements, which allow for maximum choice and control of the users over where, how and with whom to live. The users leaving institutions should be provided with a variety of options and with the necessary support by family members, professionals or peers in deciding where to live and how to organise their lives (see Chapter 7, Development of individual plans).

Ideally, the child's transition to independent living will be facilitated by a designated specialised person. The support should not stop once they have made the transition to independent living, it should continue for as long as necessary. As with adults, access to peer-support and advocacy should be ensured. Re-institutionalisation of children over the age of 18 should be avoided at all costs.<sup>230</sup>

### 5.1 Accessible housing

For many people with disabilities and older people, the availability of affordable, accessible, non-isolated and safe housing is crucial. Therefore, policies should be adopted to ensure access to social housing and to increase the number of universally designed flats or houses in the community. The term 'universal design' means "design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design".<sup>231</sup>

### 5.2 Supported living

Supported living was developed as an alternative to group homes. In group homes, people cannot choose with whom they want to share their accommodation and the support they receive is provided as part of a package with housing. By contrast, in supported living people can choose who they want to live with, in housing that they own or rent. They also receive personnel support from agencies that do not control the accommodation. Thus, they have more control over the services they receive and the same housing rights as other citizens.

There are different ways in which supported living could be organised, for example with personnel on the site only during the day, 24/7, or without permanent staff. Research in the field of intellectual disabilities and mental health problems<sup>232</sup> suggests that the elements of best practice in the provision of housing with care/support are:

- **Dispersed housing:** "apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population"<sup>233</sup>.
- **Access to mainstream health and social services:** the housing should be seen as a living place, not a place for treatment.

230 United Nations Guidelines on the Alternative Care of Children, para. 132.

231 United Nations Convention on the Rights of Persons with Disabilities, Article 2 (Definitions).

232 Goering, P. et al., *op. cit.*; Mansell, J. & Beadle-Brown, J., *op. cit.*; Ericsson, K. (2005) *A home for participation in community life: on a key task for disability services*, Uppsala University, Department of Education; Health Service Executive, *op. cit.*

233 *Time to Move on from Congregated Settings: A Strategy for Community Inclusion*, Report of the Working Group on Congregated Settings, p.71.





- **Provision of flexible, individualised support:** support that will allow the person to live independently in his/her own home and be included in community.
- **Individual choice:** for example, the user can choose whether to live alone or to share the accommodation and in which community activities to participate.

It is also recommended that the provision of social care is not tied to the provision of housing. Thus, the user will have greater choice over the support they receive and the change in the accommodation will not necessarily require a change of service provider and vice versa.

### CASE STUDY 19: SUPPORTED LIVING FOR PEOPLE WITH INTELLECTUAL DISABILITIES

In the United Kingdom, KeyRing has set up a series of networks to support people with intellectual disabilities to live in the community.

Each network is made up of ten people living close to one another: nine who live in their own homes but need support, and one Community Living Volunteer. The aim of the networks is for the members to support and assist each other with daily living skills and activities, with the volunteer seeing members regularly and helping the group to work together. The volunteer also supports other members of the network to explore events taking place locally and to get involved in them. Paid Community Support Workers and Supported Living Managers can provide additional support services if required.<sup>234</sup>

## 5.3 Alternative family-based options for children

When it is not possible for the child to remain (prevention) or to return (reintegration) to live with their parents, then alternative forms of care must be considered. A range of different care options should be developed, so that the most appropriate form of care is provided, corresponding to the best interests and needs of each individual.<sup>235</sup> Examples include:

### 5.3.1 Kinship care

This is defined as “family-based care within the child’s extended family or with close friends of the family known to the child”.<sup>236</sup> Kinship care could be formal (ordered by a relevant administrative body), or informal (private arrangements within the family). The benefits of this form of care for the child are that they can remain in familiar surroundings and stay in touch with their culture and traditions. It should be noted, however, that private arrangements should also be subject to review by the relevant authorities.

### 5.3.2 Foster care

Refers to “situations where children are placed by a competent authority for the purpose of alternative care in the domestic environment of a family other than the children’s own family that has been selected, qualified, approved and supervised for providing such care.”<sup>237</sup> There could be different types of foster care, for example:

<sup>234</sup> Extract from the European Union Agency for Fundamental Rights *op. cit.* (2012a), p.33. For more information, see: <http://www.keyring.org/home>

<sup>235</sup> United Nations Guidelines on the Alternative Care of Children, para. 54.

<sup>236</sup> United Nations Guidelines on the Alternative Care of Children, para. 28.

<sup>237</sup> United Nations Guidelines on the Alternative Care of Children, para. 28, c, ii.





- **Emergency foster care:** This is used to remove the child from a particular situation because of harm or risk of harm. Meanwhile, efforts should be made to find a long-term solution, either by supporting reintegration into the child's family, if this is possible and in the best interest of the child, or by considering other alternative measures.
- **Long-term foster care:** Usually the preferred measure for long-term care for children who cannot be reintegrated in their families is adoption. However, long-term foster care can be suitable for some children. The choice of the most suitable option should be based on the best interests of the child.
- **Short-term and medium-term foster care:** Could be suitable for a period of time for children who cannot be looked after by their parents, but for whom reunification with their family at a later period is possible.
- **Specialist foster care:** Specially trained foster carers, who are provided with additional support to provide care for children with complex needs, such as severe, multiple disabilities or terminal illness.
- **Remand foster care:** Provide supporting family environment to young people who have been remanded by the Courts into public care.
- **Respite foster care:** Regular periods of short-term foster care, offering the child a break away from home and the family or carers a break from their caring responsibilities.
- **Parent and child foster care:** Gives an opportunity to parent/s and their children to stay together and receive support from the foster carer.

### 5.3.3 Adoption

This is a permanent measure, in contrast to foster care, where the assumption is usually that after a certain period the child will move on. Adoption should be seen as a measure of last resort, because the placement in an adoptive family will make the reunification of the child with their own family impossible for the remainder of their childhood. Therefore, adoption should be considered only when all possibilities for reintegration have been explored and it has been found that reintegration is not possible.

For children in these circumstances, the security of a permanent family is often important. However, in traditional adoption all ties with the birth family are permanently severed. Therefore the older the child, the higher the risk of adoption breakdown. As a result, some countries have developed a system of 'open adoption', where the new family becomes the child's permanent family, but some contact with the birth family is maintained.<sup>238</sup>

Some countries continue to practise 'secret' adoption, where the child is not informed that they have been adopted. This can cause problems of identity later on and can precipitate adoption breakdown. All adoption providers should be obliged to prepare potential adoptive parents so that they understand the importance of informing a child of their adoption and their past.

Concerns have been raised about the high rates of inter-country adoptions from some countries.<sup>239</sup> Instead of relying on this form of care to support the process of deinstitutionalisation, countries should focus on promoting programmes for prevention and re-integration, as well as the development of family-based alternative care options. This involves provision of accessible support to foster and kinship families and a monitoring system, which will help to avoid the risk of repeated

<sup>238</sup> Alty, C. & Cameron, S. (1995) "Open adoption – the way forward?", *International Journal of Sociology and Social Policy*, Vol. 15 Iss: 4/5, pp.40–58.

<sup>239</sup> UNICEF *op. cit.* (2010).



violence or separation. Small-scale residential care options should be in place for cases where such a placement might be in the best interest of the child. Inter-country adoptions might be considered an option, but *only* “if the child cannot be placed in a foster or an adoptive family or cannot in any suitable manner be cared for in the child’s country of origin”.<sup>240</sup>

#### 5.3.4 Group homes

Group homes or similar residential care (in which groups of people, children or adults, live together in a house or a flat with support from staff) are being increasingly used in the process of deinstitutionalisation. However, group homes should not become the main alternative to institutions and their development should be carefully considered.

The Council of Europe Commissioner for Human Rights has raised a number of criticisms of group homes.<sup>241</sup> He points out that group homes often do not differ much from institutions as they restrict the control of the people over their lives and isolate them from the community, despite being physically located within a residential area. Clustering children or adults in the community draws attention to them as a group rather than as individuals and sets them apart from the rest of the neighbourhood. In addition, linking support services with housing in group homes limits the choice of the people about where they can live.

Systematic placement of children with disabilities in group homes without ensuring equal access to prevention, re-integration or family-based care should be avoided at all costs.

At the same time, small-scale residential care in the form of small group homes in family-like environments can sometimes be used as temporary or last resort<sup>242</sup>, if it is in the best interest of the child (for example, in a case of continuous placement breakdown), or if it is based on the child’s or young person’s own informed decision. The use of such settings should always be limited to cases where a properly conducted, professional assessment has deemed them appropriate, necessary and constructive for the individual child concerned and in their best interest. The objective of any residential care should be to “provide temporary care and to contribute actively to the child’s family reintegration or, if this is not possible, to secure their stable care in an alternative family setting”.<sup>243</sup>

For older people, residential arrangements such as group homes are sometimes considered preferred options. People live in their own flat with their own belongings while benefitting from common services (such as a restaurant and other facilities) and enjoy the company of peers. However, a range of alternative community-based options needs to be provided in order to ensure that people have real choice of where and how to live. It must also be noted that the ‘choice’ of an older person to move to a group facility and distance themselves from the rest of society is likely to be influenced by society’s view of older people as a ‘burden’.

In summary, group homes could be developed as part of a deinstitutionalisation strategy, but this should clearly be for a small minority of users for whom an assessment shows this is a positive care/support choice. They should not be seen as “the default solution that presumes to embody the principles of the right to live in the community”.<sup>244</sup> More efforts should be invested in removing barriers in the environment, the provision of accessible housing, the development of supported living arrangements and of alternative family-based care options for children.

240 United Nations Convention on the Rights of the Child, Article 21(b).

241 Commissioner for human rights, *op. cit.* (2012), p.27.

242 UNICEF *op. cit.* (2010), p.19.

243 United Nations Guidelines for the Alternative Care of Children, para. 122.

244 Commissioner for Human Rights, *op. cit.* (2012a), p.27.





## CASE STUDY 20: COMMUNITY-BASED CARE IN ENGLAND AND THE REPUBLIC OF MOLDOVA

In one county in England, there are 2,400 children with disabilities. Because universal health and education services are accessible, only 1,600 of these children require additional care and support services. The overwhelming majority of these children live with their families who are provided with a range of support services, from in-home support to short breaks. Only 17 children live in residential care, equating to 0.7% of the total population of children with disabilities. In this instance, the care that is provided is high-quality and extremely expensive, but it meets the needs of a small group of children with very complex needs. It should be noted that because such a small number of children require residential care, the county can afford to spend more on each care placement, making it possible to provide higher quality care.

In the Republic of Moldova, two counties developed plans for complete deinstitutionalisation, including the closure of two institutions for children with disabilities. At that time, the two institutions were caring for more than 270 children and initially the local authorities envisaged that five small group homes would be required. However, following intensive work to support families and recruit specialist foster carers, only two small group homes were needed. These were both for older teenagers, who had lived in the institutions for many years and lost all contact with their families.

## Further reading

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## Tools

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## CHAPTER 6: ALLOCATING FINANCIAL, MATERIAL AND HUMAN RESOURCES

*This chapter considers the resource implications – financial, material and human – of moving from institutional to community-based care. Because of its complexity, this process requires careful planning, coordination and control. For reform to take place, it is crucial that funding commitments are built into policies and that deinstitutionalisation plans take account of both available and required resources.*

*This chapter is largely based on the European study ‘Deinstitutionalisation and community living: Outcomes and costs’,<sup>245</sup> which is the most comprehensive research into this area to date.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

Some articles of the Convention, including parts of Article 19, are subject to the so-called progressive realisation of rights. This is in recognition of the fact that the implementation of social, economic and cultural rights (not just under the CRPD, but also other human rights treaties) depends upon specific measures being undertaken, which may be subject to resource constraints. For example, ensuring access to the full range of community support services, as required by Article 19, will require considerable resources in countries where very few community-based services are in place.<sup>246</sup> At the same time, each State has an obligation to undertake measures to the “maximum of its available resources [...] with a view to achieving progressively the full realisation of these rights, without prejudice to those obligations [...] that are immediately applicable according to international law”. (Article 4(2))

### Obligations under the UN Convention on the Rights of the Child

As is the case with the CRPD, those articles in the CRC covering economic, social and cultural rights (such as the rights to health, education and to an adequate standard of living) are also subject to progressive realisation. According to Article 4, States must “undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international cooperation.”

## 1. Planning stage

The interconnection between costs, needs and outcomes should be central to any discussion and decision on the future system of service provision, whether it is for children, people with disabilities or older people. The success of a particular system in improving health and quality of life depends on the mix, volume and deployment of resource inputs, including personnel, family inputs, buildings and other capital, medications and the services they deliver. These in turn are dependent on the finances available through various funding routes. The outcomes should be defined separately for different user groups, but what is common to all is the need to consider quality of life.<sup>247</sup>

<sup>245</sup> DECLOC Report, p.52.

<sup>246</sup> Parker, C., *op. cit.*, p.15.

<sup>247</sup> DECLOC Report, pp.57–58.



## 1.1 Comparing the cost of institutional care and community-based services

When looking at the economic implications of community-based services versus institutional care, it is vitally important to take into consideration both the costs and quality. The comparison between different services has to be made on a like-for-like basis, in terms of characteristics of people who use the services, the costs and the quality.<sup>248</sup> In planning the transition, it is important to consider everyone who needs services, whether they are living in institutions or in the community. Decision-makers should plan for a system of services in the community that will meet everyone's needs, including universal preventive approaches.

It should also be noted that a number of services are provided by the informal care sector, such as families, friends, neighbours and volunteers. While this may be perceived as 'free' care, the reality is that high burdens and costs often fall on families, whether it is loss of employment or stress-related illnesses.<sup>249</sup> This should be addressed during the planning and implementation stages. The cost implications of informal care should also be taken into account.

In some institutions, residents themselves may carry out some work, providing cheap or free labour which could reduce the cost of institutional care. It is important to ensure that people are not forced to provide free labour or to remain in institutions longer than others (perhaps with higher support needs) simply for the unpaid work they carry out.

Furthermore, when comparing the cost of institutional versus community-based care, it is important to consider the wider economic implications of deinstitutionalisation. As explained in Chapter 1, investment in services for children 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 behaviour or criminality – all of which have resource implications.<sup>250</sup> Similarly, in mental health, economic evidence shows that greater investment in community-based services produces benefits beyond health care, such as "increased productivity, reduced contact with the criminal justice system and improved rates of social inclusion". In addition, the contribution of mental health problems to the overall disease burden, combined with the availability of effective and cost-effective prevention and treatment, justifies increased investment in community-based mental health services.<sup>251</sup>

At the same time, the development of national policies and action plans must go hand-in-hand with awareness-raising activities. These should seek to reduce the stigma associated with mental health problems and institutional care among the general population, with the aim of mobilising support for reform.

## 1.2 Structure of service provision

An important part of the planning process is to understand the structure of service provision. Not all needs can be catered for by the same sector. For example, a person with disabilities may have

<sup>248</sup> *Ibid.*, p.48.

<sup>249</sup> *Ibid.*, p.49. See also Triantafillou J. et al. (2010), *Informal care in the long-term care system – European overview paper*, Athens/Vienna: CMT Prooptiki Ltd./European Centre for Social Welfare Policy and Research (INTERLINKS Report #3 – <http://interlinks.euro.centre.org/project/reports>).

<sup>250</sup> See, for example, Walsh, K., Kastner, T. & Green, G., "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research", *Mental Retardation*, Vol. 41, 2003, pp.103–122.

<sup>251</sup> McDaid, David et al. (2005) *Policy brief, Mental Health III, Funding mental health in Europe*. Brussels: European Observatory on Health Systems and Policies, pp.9–10.



needs that should be met by the social care sector, as well as health care, housing or education providers, as well as others. Good coordination is therefore crucial in order to avoid gaps or overlaps in service provision which constitute an inefficient use of funding. This may be further complicated by the fact that services are provided by the State, non-governmental organisations and private providers.<sup>252</sup>

### CASE STUDY 21: DIVERSIFICATION OF SERVICE PROVISION IN ENGLAND

In England, diversification of providers of services and alternative care has been a government policy since the early 1990s, beginning with initiatives such as Choice Protects and Quality Protects. The aim was to support local authorities not just to develop their own quality services, but to develop skills in commissioning services, such as foster placements provided by NGOs. Currently, 74% of children in alternative care in England are in foster care and 35% of these are with NGO providers. The development of the independent sector in England has not only increased the choices of placements for children and brought more foster carers into the profession, but has also been instrumental in raising standards for foster care across the whole sector.<sup>253</sup>

## 1.3 Financing arrangements

In addition to the structure of service provision, planning for future services must take into account the current financing arrangements, in other words, how funding is raised. For example, social and health care services may be financed through taxation, through payments by service users or their families ('user charges'), through private insurance, or through social insurance linked to employment. What needs to be considered is whether the way services are funded creates a barrier to deinstitutionalisation; for example, health care, social care and housing may be financed in different ways. In some countries, health care is available to all who need it, but social care is means-tested and financed through user charges, which can then lead to under-utilisation of services. It is also possible that the way services are funded will facilitate the process of reform.<sup>254</sup>

In order to ensure the most equitable and cost-effective use of resources, 'regulatory mechanisms' should be developed "including eligibility criteria and sound and fair assessment procedures".<sup>255</sup>

The WHO/World Bank Report on Disability highlights that mechanisms based entirely on user charges are the least equitable.<sup>256</sup> This is of particular concern for people with mental health problems, where the shifting of community-based services out of the health and into the social care sector can have implications for the entitlement and access to services. If access to services within the social care sector is restricted or affected by being means-tested or by depending on a disability assessment, it can lead to inequity in access to, or the provision of, services.<sup>257</sup>

<sup>252</sup> DECLOC Report, p.46.

<sup>253</sup> UK Department for Education, Statistical First Release, SFR 21/2011, 28 September 2011, <http://www.education.gov.uk/researchandstatistics/statistics/a00196857/childrenlooked-after-by-localauthorities-in-engl>

<sup>254</sup> DECLOC Report, p.47.

<sup>255</sup> World Health Organisation & World Bank, *op. cit.*, p.150.

<sup>256</sup> *Ibid.*, p.149.

<sup>257</sup> McDaid, David et al. *op. cit.*, p.8.







The three elements that should be present in a system to ensure fair access to services are:

- adequate resources to provide the services to all in need;
- fair assessment processes; and
- the opportunity to challenge decisions about eligibility.

## 1.4 Funding routes

How funding reaches the services should also be considered in the planning stage:

- In some countries, finances are raised centrally and then allocated directly to providers.
- Another option is to allocate centrally-raised funding to commissioners, who are responsible for assessing overall and individual needs, identifying potential service providers and then entering into a contractual relationship with them. In this case, it is important that the length of the contract gives providers sufficient security. Another consideration is whether joint commissioning is needed between health, social care or housing bodies, for example.
- The third possible funding route is consumer-directed care, where individual service users or their carers are given responsibility for purchasing services to meet their own needs.<sup>258</sup> In this case, it is important that service users have a range of services to choose from and that adequate support is provided to service users to help them manage their budgets.

NGOs can also be commissioned to provide services; there is evidence that they can respond more flexibly to the changing local circumstances than state providers.<sup>259</sup> None of these options are mutually exclusive, but the funding available to service users to access or purchase services must meet their needs and requirements.

The various welfare benefits or allowances paid to people with disabilities, carers or parents of children with disabilities should also be considered.<sup>260</sup> What should be avoided is people having to choose between the various benefits and allowances, and paid employment. For example, a person with disabilities should not lose their allowance covering the higher cost of living with an impairment (as well as the necessary assistive devices) if they decide to take up employment. Similarly, carers should be able to combine caring responsibilities (and the relevant benefits/allowances) with other paid employment.

## 1.5 'Hump' and double running costs

The budget attached to any deinstitutionalisation strategy must take account of the 'hump' and double running costs (also referred to as 'parallel' or 'transitional' costs). Hump costs refer to the initial investment in the new community-based services which is likely to be high, especially if services in the community are underdeveloped or lacking.<sup>261</sup> Hump costs are also referred to as the 'capital investment' and will include, for example, the purchase of new housing in the community, furnishings and clothing, as well as personnel training. An accurate projection of capital investment expenditure is necessary for the success of the transition process.<sup>262</sup>

<sup>258</sup> DECLOC Report, pp.48–49.

<sup>259</sup> McDaid, David et al. *op. cit.*, p.14.

<sup>260</sup> DECLOC Report, p.54.

<sup>261</sup> *Ibid.*, p.84.

<sup>262</sup> Mulheir, G. & Browne, K. *op. cit.*, p.89.







It is clear that institutions cannot be closed until new community-based services are in place. This means that, for a certain period of time, until transition is complete, institutional and community-based services will have to run simultaneously, leading to double or parallel running costs.<sup>263</sup> Not everyone will leave the institution at the same time; as a result, there will be some personnel and maintenance costs until the last person leaves. It is important that this process is not rushed with a view to reducing costs, as it could lead to people having to move to inadequate settings or being denied adequate care. The safety of those still in the institution must also be ensured.<sup>264</sup>

Double running costs can be dealt with by identifying transitional funding and by carefully managing the closure of the old services and the establishment of new community services.<sup>265</sup> The need for forward planning – projecting costs and identifying funding – is also highlighted, in order to reduce the length of the transition period and minimise costs.<sup>266</sup>

#### KEY GUIDANCE 10: THE POTENTIAL FOR EU FUNDING TO SUPPORT TRANSITIONAL COSTS

EU funding –Structural Funds and the Instrument for Pre-Accession Assistance – can be used by Member States, acceding and candidate countries to cover some of the double running costs in the process of transition from institutional to community-based care. To do this, it is important that the deinstitutionalisation of different groups is identified as one of the priority actions in the Partnership Contracts and the Operational Programmes for the upcoming programming period.

Structural Funds can support investments in a number of areas of reform, including:

- infrastructure – such as housing, as well as home adaptations;
- training of personnel to work in the new services;
- creating employment opportunities in the community; and
- technical assistance, involving assessment of the needs and the coordination or management of the entire process of change.

The list of indicative actions, checklists for the programming of Structural Funds use, example output and result indicators and indicators for the selection of projects can be found in the Toolkit on the use of European Union funds for the transition from institutional to community-based care.

263 DECLOC Report, p.84.

264 Power, *op. cit.*, p.23.

265 Mulheir, G. & Browne, K. *op. cit.*, p.89.

266 Power, *op. cit.*, p.23.





## 2. Workforce considerations

### 2.1 Maintaining a skilled workforce

One condition for establishing and running new services in the community is the availability of skilled personnel. An inability to find enough people with the right skills, including to manage services and to retain them, can be a serious barrier to developing and sustaining high-quality community-based services. Many personnel currently working in the institution will, given appropriate training, be able and willing to work in community-based services. For some, however, this will not be an option, either because they cannot be retrained or are not interested or able to work in the new services.<sup>267</sup>

Motivating the workforce and addressing workforce issues as part of the institutional closure process is critical to the process of moving from institutions to community-based services. It can involve engaging the trade unions in the planning stages. Moreover, experience shows that working closely with care personnel in developing services in the community has been beneficial to the process, in the sense of helping to bring everyone on board and avoiding resistance.<sup>268</sup>

Serious consideration should be given to personnel remuneration, benefits and working conditions, both to attract them to work in the new services and to prevent rapid turnover. Ensuring that personnel are adequately paid can also help improve the quality of care.<sup>269</sup> In some countries, institutional care personnel are better paid and have better conditions than the personnel working in community services, largely because institutional care personnel tend to have nursing or medical training. This can be addressed by equalising wages, of those working in the institutions and the community during the process of transition and by providing better opportunities for working in the community.<sup>270</sup> It should be noted that the current trend in Europe is the opposite one, with the conditions of service worsening.<sup>271</sup>

In some countries, professionals who are crucial to running services in the community, such as occupational therapists and community care workers, do not exist. In order to fill this gap in professional expertise, international professional exchanges could be considered as a part of the deinstitutionalisation planning process, along with training programmes and university courses.

### 2.2 Informal care<sup>272</sup>

It is important to recognise the role of, and improve support for, family and other unpaid carers, as they are likely to provide a part (if not all) of the support. Support for carers can be provided through tax credits, social security, allowances, grants from social care budgets, pension credits, consumer-directed payments (such as individual budgets) or payments from voluntary sector bodies.

Employment-friendly policies should also be in place for those family members who would like to support their child, parent or relative while working. This could be in the form of flexible working arrangements or the possibility of taking paid or unpaid leave to care for an older ill relative. Support, counselling and respite services are also important to help carers deal with the stress of providing support.<sup>273</sup>

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<sup>267</sup> DECLOC Report, p.56.

<sup>268</sup> Power, *op. cit.*, p.29.

<sup>269</sup> DECLOC Report.

<sup>270</sup> Power, *op. cit.*, p.29.

<sup>271</sup> Information provided by the European Association of Service Providers for Persons with Disabilities.

<sup>272</sup> See COFACE, *op. cit.*

<sup>273</sup> DECLOC Report and Grundvig Learning Partnership, *op. cit.*, p.18.



It must be noted, however, that family members should not be left with no alternative other than having to provide support due to the gaps in services. Other forms of support, such as personal assistants or other paid personnel should also be available.

#### **CASE STUDY 22: CONTRIBUTION OF INFORMAL CARERS IN THE UK**

The report 'Valuing Carers 2011' by Carers UK, Circle and University of Leeds, estimated the annual contribution of informal carers in the UK to be 119 billion GBP (in comparison with 98.8 billion GBP overall cost of all aspects of the National Health Service). The number of informal carers was obtained through the national census, which for the first time in 2011 included the question: "Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old age?" It showed that in the UK, 12% of the population provided unpaid care. The report used 18 GBP as the cost of care per hour, which is an official estimate of the actual cost per hour of providing home care to an adult.<sup>274</sup>

### **3. Funding the new services**

This section looks at how funding reaches the services. Each country will have to make a decision on how services are funded, with a view to ensuring quality services that respond to the needs of the different groups, cost-efficiency and sustainability.

#### **CASE STUDY 23: REDIRECTION OF RESOURCES FROM INSTITUTIONS TO COMMUNITY-BASED CARE IN THE REPUBLIC OF MOLDOVA**

In the Republic of Moldova, one NGO has worked closely with the Ministry of Finance for four years in order to develop methods for ring-fencing and redirecting resources from institutions to community-based care.

In one county, local authorities developed a plan for the comprehensive deinstitutionalisation of children's services, including the closure of three institutions. All three institutions were funded centrally by the Ministry of Education. The community services required (including social services and inclusive education) would be funded by the county council. The NGO worked with the Ministry of Education, Ministry of Finance and county councils to develop a three-stage process for redirecting finances. Firstly, the budgets for the institutions were protected and it was agreed they would not be subject to reduction as the numbers of children in the institutions reduced. Secondly, the budgets were decentralised to the responsibility of the County Council, while the institutions were still open. This decentralisation was based on the condition that the local authority would not reduce the budget or direct the finances to anything other than children's services. Thirdly, as the institutions gradually closed, the budgets and personnel posts were transferred to the new community-based services, making it possible for the County Council to sustain the new services in the future.

*It should be noted that Moldova is the poorest country in Europe by some distance and has been hit harder by the global financial crisis than any other country in the world.<sup>275</sup> Despite this, it has been possible to close institutions and transfer resources to community-based services.*

274 Carers UK, Circle and University of Leeds (2011), *Valuing Carers 2011, Calculating the value of carers' support*, available at: [http://www.carersuk.org/media/k2/attachments/Valuing\\_carers\\_2011\\_\\_Carers\\_UK.pdf](http://www.carersuk.org/media/k2/attachments/Valuing_carers_2011__Carers_UK.pdf)

275 The World Bank (2010), *The Crisis Hits Home: Stress-Testing Households in Europe and Central Asia*.



### 3.1 Ring-fencing the funding

When closing down an institution, the institutional budget should be ‘ring-fenced’ (set aside) for community-based services that will serve the same group of people. For example, in the case of a psychiatric hospital closure, the budget should be ring-fenced for person-centred community mental health services. This is to prevent the funding being lost to other policy areas. In this respect, there is a possibility of using ‘protected budgets’, whereby funding follows an individual regardless of where they receive services. In such cases, the level of protected budget needs to be monitored regularly to ensure that it is consistent with the level of the need.<sup>276</sup>

There is also an argument for integrating funding into mainstream services, such as health or social care services, as opposed to ring-fencing it for services for people with disabilities, for example. This can ensure that money is used innovatively, such as for preventive services or for treating mental and physical health problems at the same time. However, in an integrated system, there is a danger of funding being lost to other priorities.<sup>277</sup>

Whatever the decision, it is important that no negative incentives are unintentionally created by the way funding is allocated. On the contrary, it needs to create the right incentives for cross-sector work and to address the needs of all in need of services.

### 3.2 Risks: the ‘paradox of funding’

An important disincentive for the development of prevention and family or community-based care can lie in the system of funding and in the division of resources between central and local authorities. In some European countries, the State directly finances institutions, often proportionally to the number of residents. In the absence of disincentives and a moratorium on new placements, institutions will keep attracting children and adults into their services in order to keep the ‘funds’ coming in.

Furthermore, the burden of expenditure for family and social services is often shouldered by the local authorities, which also have an interest in transferring children and adults into centrally-funded institutions in order to preserve local budgets. The paradox lies in the fact that people are institutionalised to save money, even though institutions have generally been proven to be more expensive than prevention or reintegration of children and adults into their family of origin or the community.

Therefore, whenever a deinstitutionalisation process is in place, it is essential to ring-fence the funds and to reinvest them into quality alternative care, social services and family support in the community. As a minimum, these funds should correspond to the amount that was allocated for each child living in the institution.<sup>278</sup>

### 3.3 Centralised or devolved funding

Whether budgeting responsibilities are centralised or devolved (de-centralised) to a regional or local level will vary from one country to another. It is suggested that devolved budgets and purchasing of services increase the likelihood of services responding to the assessed needs and

<sup>276</sup> McDaid, David et al. *op. cit.*, p.12.

<sup>277</sup> DECLOC Report.

<sup>278</sup> Eurochild *op. cit.* (2012a), p.18.



expressed preferences of individuals. Service professionals tend to be closer to the users and are in a better position to recognise the needs of their local community. Devolved budgets increase the likelihood of shifting the balance of care from reliance on institutions.

The disadvantages of devolved budgets are having less information and fewer technical resources to process the information. In addition, they do not include a fall-back position if financial mistakes are made. Decentralised decision-making therefore requires a well-planned budget allocation mechanism and robust accounting procedures. Because financial risks are bigger, it might encourage more conservative or 'safe' use of funding, hampering innovation.

Centrally-controlled budgets allow risks to be spread and give greater purchasing power. They might also make it easier to respond strategically to countrywide needs, or to the needs of a specific area. If controlled centrally, budgets can be spread more evenly across the country, facilitating more equal access to services and quality provision. However, with a centralised budget, there are few incentives for local authorities or professionals to make services more cost-effective, as this could mean they are allocated less funding in the future.

Whether funding is centralised or devolved, it is necessary to apply formulae to work out how much funding should go to local authorities or to individual providers. These formulae should reflect the distribution of needs and agreed policy priorities. Ideally, they should be based on an independent measurement of needs, taking account of the socio-demographic make-up of the local population, social deprivation, morbidity and cost variations.<sup>279</sup>

### 3.4 'Consumer-directed' care

The commissioning of services has a direct impact on their delivery and there is no simple blueprint for success. The principle of responding to local circumstances and needs would apply in this case as well.<sup>280</sup>

'Self-directed' (or 'consumer-directed') care, collectively referred to as 'self-determination programmes', is a more recent and increasingly popular development in service provision. The aim is to give more independence and choice to service users, giving them greater control over their lives. The key principle is that funding is handed over to those individuals who wish it, in the form of direct payments or personal/individual budgets; they then purchase their own care. This arrangement emphasises independence and empowerment and can improve quality of care, while also being cost-effective. Consumer-directed care arrangements can also help break down barriers between services, sectors and budgets, because funding can be used across sectors, such as health, social care, housing and education, as well as culture and leisure.

At the same time, consumer-directed care places more responsibility on individual users or their families. Problems can arise if the funding is too low to allow budget holders to access services they need, or if the necessary services are not in place (i.e. if funding is linked to limited choice options).<sup>281</sup> There is also some risk of exploitation, though this can be dealt with by providing expert support to potential budget holders.

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<sup>279</sup> DECLOC Report.

<sup>280</sup> *Ibid.*

<sup>281</sup> Power, *op. cit.*, p.25.



The transition to consumer-directed care is a complex process, involving the “design of an individual budget allocation model and embedding short and medium-term options for moving people over to the new system.”<sup>282</sup> One of the main challenges is moving from existing block contracts to individualised procurement. Experience shows that this cannot be done in haste. It is suggested that governments might want to use ‘innovation grants’ to encourage the on-going development of good practice in individualised funding options, in preference to block grants or contracts for a certain service or set of services. This is based on the premise that service provision should not be built around block funding, but on a model which searches for creative options, allows for demonstration projects and seeks to tailor support to different groups.<sup>283</sup>

#### **CASE STUDY 24: PERSONAL EXPERIENCE OF A YOUNG PERSON WITH DISABILITIES USING A PERSONAL BUDGET IN THE UK (EXTRACT FROM INCONTROL<sup>284</sup>)**

Jonathan is a disabled teenager. His quality of life has been transformed since he left school in July 2008 with an individual budget. Now he and his mum decide what he should do, when he should do it and who should support him. Jonathan’s complex health condition means he receives funding through continuing health care. He was fortunate enough to be part of a pilot run by the Learning and Skills Council giving individual learning support funds. Putting the different funds together has enabled Jonathan to employ one full-time personal assistant (PA) and two part-time PAs for activities in the evenings and on weekends.

Jonathan’s mum reports an “amazing improvement in his quality of life. ...It has given him so much more freedom to explore life. Without his individual budget he would not have been able to do anything like the things he can do now. I would have had difficulty taking him to these things. It is encouraging Jonathan to have a bit of an independent lifestyle. And with Jonathan having his PAs, I have more time to spend with my other two sons who both have learning difficulties. And Jonathan can’t stop smiling!”

In addition to enjoyment and happiness, Jonathan’s learning needs are fully taken care of. His week – tailor-made for him – allows many opportunities for developing his independent life skills, his special interest in computers, multi-media and individual tuition.

### **3.5 Multiple funding sources**

Shifting the balance of care from institutions to community-based services will also affect the balance of funding – from exclusive reliance on social care or health systems (often a part of a single, consolidated institution budget) to a number of services that are funded from different budgets. A person with disabilities will, for example, not only have health needs, they may also require support at home and to go about their everyday lives. They might need housing adaptations or access to social housing and/or support in finding or retaining paid employment. Similarly, family carers might have needs associated with the burden of providing care. The same will be the case with other user groups and their various environments, all of which will have to be considered.

The challenge of having multiple funding sources is coordination and not knowing how to assess and manage the entitlements of potential service users. Problems can arise because of differences

<sup>282</sup> *Ibid.*

<sup>283</sup> *Ibid.*, pp.26–27.

<sup>284</sup> See: [http://www.in-control.org.uk/related-pages/what-we-do/children/personal-stories-\(children\)/joined-up-support.aspx](http://www.in-control.org.uk/related-pages/what-we-do/children/personal-stories-(children)/joined-up-support.aspx)



in entitlements and access and because of the potential for unintended negative incentives created in some systems as a result of performance targets. Fragmentation of decision-making and the barriers created by 'silo' budgets (with funds earmarked for one use and not transferable to another) have been identified as the cause of the problem. Poor coordination can result in wasteful overlaps between the services, or gaps in the support spectrum.

In fact, coordination has been identified as the biggest challenge in providing community-based services. Several possibilities have been suggested as to how coordination can be improved. They include:

- agreeing to a shared plan for action;
- designating one organisation as the lead agency with responsibility for strategic coordination across sectors;
- putting in place 'care brokers' to assess needs and coordinate service responses;
- reaching agreements to facilitate the movement of money between different national or local budgets;
- establishing joint budgets across health, social care, housing or other agencies; and
- putting in place consumer-directed care arrangements.<sup>285</sup>

#### **CASE STUDY 25: EXAMPLE OF GOOD COORDINATION IN SERVICES FOR OLDER PEOPLE IN FINLAND<sup>286</sup>**

Finland is divided into hundreds of municipalities (336 in 2011), which are responsible for providing health and social care for their inhabitants. A municipality might provide the services itself or together with other municipalities. In South Karelia, an integrated organisation – the South Karelia Social and Health Services (Eksote) – was established in 2010. Eksote is a regional social and health district where the primary and secondary health and social care services of eight municipalities are integrated within the same organisation.

The integrated organisation creates excellent possibilities for developing social and health care services for a larger area as a single entity. Eksote's organisational structure facilitates agreement, coordination and cooperation between different forms of care and services (domiciliary services, home care, sheltered housing services, rehabilitation, acute hospital care and long-term care) as well as between different professionals. Eksote's goal is also to develop processes that increase productivity of work without decreasing the quality of care. Eksote's way of organising services has been adopted as a national example of good practice in organising social and health care services. The main message is that a larger, integrated organisation can provide client-centred services near to the clients in less-populated areas.

The main benefit of this integrated service model is that it improves older people's quality of life by supplying adequate services and care at the right time based on clients' needs. In addition, the integrated service processes are more functional, cost-effective and client oriented.

<sup>285</sup> DECLOC Report.

<sup>286</sup> For more information, see Interlinks: Health systems and long-term care for older people in Europe. Modelling the interfaces and links between prevention, rehabilitation, quality of services and informal care, <http://interlinks.euro.centre.org/model/example/ManagingClientOrientedProcessesInAnIntegratedOrganisation>





## 4. Turning barriers into opportunities

Closing down institutions and developing services in the community is a life-changing experience for the people living there, but it also affects both those working in the institutions and the local community. It is important to turn potential barriers to deinstitutionalisation into opportunities.<sup>287</sup>

### 4.1 Effect on the local economy

Institutions can be the main employer in a local area, especially if they are large and in remote locations where there may be few other employment opportunities. Closing the institution can therefore have a major effect on the local economy and can lead to heavy job losses. Community-based services are likely to be scattered around the country (since they will follow the people) and the personnel may be unwilling or unable to move. At the same time, there may be new services that will be developed in the area, offering opportunities for local development. The building itself may be used for a different purpose, which again can provide new employment opportunities.

Similarly, when older people are well-integrated in the local community in line with the policy on active ageing, they also can become important consumers of goods and services of a very different nature. This may considerably boost the local economy and labour market and have secondary effects on public budgets.

### 4.2 Making use of existing buildings

The value of the buildings which house the institutions and the land they are situated on has to be taken into account when comparing the cost of institutional versus community-based care.<sup>288</sup> The value will vary, depending on the state of the buildings and their location. It is possible that it will be very low or that there will be no appropriate alternative use for the building.

Plans for the future use of the building should be made as part of the process of closure. They should involve the personnel and local community in order to reduce resistance to closure. While it is important to be creative and open-minded to new possibilities, it is also important to ensure that no part of the building is used to provide institutional care, for any group of people. If conveniently situated, the building could, for example, be used to house offices for integrated community services, such as community-based social workers, mobile therapists or therapeutic teams. Former institutions can also be converted into schools, hospitals or social housing (apartment blocks).<sup>289</sup> Ideally, the capital will stay in the social care, health or education sector and will not be lost to other sectors. This is further elaborated on in the section on ring-fencing the available funding in Chapter 6.

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<sup>287</sup> DECLOC Report.

<sup>288</sup> DECLOC Report.

<sup>289</sup> Mulheir, G. & Browne, K. *op. cit.*, page 91.





## Further reading

Fox, L. & Gotestam, R. (2003) *Redirecting Resources to Community-based Services: A Concept Paper*. Washington, D.C.: World Bank.

Hurstfield, J. et al. (2007) *The costs and benefits of independent living*. London: Office for Disability Issues, HM Government.

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Quinn, G. & Doyle, S. (2012) *Getting a Life: Living Independently and Being Included in the Community, Legal Analysis of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the UN Convention on the Rights of Persons with Disabilities*, Office of the High Commissioner for Human Rights.

Rodrigues, R. & Schmidt, A. (2010) *Paying for Long-Term Care*, Policy Brief September 2010. Vienna: European Centre.

Triantafyllou, J. et al. (2010) *Informal care in the long-term care system*, European Overview Paper, Vienna: Interlinks.

## Tools

Grundtvig Learning Partnership, *Self-assessment of their needs by family carers: The pathway to support*, available at: <http://www.coface-eu.org/en/Projects/Carers-Project/>

Mental health economics European network, Phase II: <http://www2.lse.ac.uk/LSEHealthAndSocialCare/research/PSSRU/mheen.aspx>

WHO CHOICE – A database on the cost-effectiveness of interventions for mental health in Europe: <http://www.who.int/choice/en/>



## CHAPTER 7: DEVELOPING INDIVIDUAL PLANS

*The purpose of an individual plan is to ensure consistency between what a person needs, how they wish to live their life and the support they receive.*

*This chapter considers the different elements of the planning process: assessment and self-assessment; development of individual care and support plans; implementation; and review of plans. It highlights the importance of ensuring the meaningful participation of users and where relevant, their support persons, families or carers, in all stages of the planning process.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

State Parties are required, under Article 26 of the CRPD to “take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence” and “full and effective inclusion and participation in all aspects of life”. Services developed in the areas of health, employment, education and social services, must be based on the “multidisciplinary assessment of individual needs and strengths”. They should also be available to persons with disabilities as close as possible to their own communities, including in rural areas. As regards children with disabilities, their “best interests” should be a primary consideration (Article 7).

## 1. Involving users

Planning involves making important decisions about the lives of the users. This could include, for example, where an adult or a young person will live after they leave the institution or care: with family or friends, in their own flat or house, in supported housing or in another residential community-based alternative. In relation to children, decisions involve who will look after the child: whether the child can return to their family, or whether alternative care options will have to be considered, such as family-based care, foster care, residential care or adoption. It is essential that these decisions are made with the active involvement of the users, and where relevant, their advocates, enabling them to have control over their lives and the support they receive.

### 1.1 Children

As a whole, the involvement of the child in the decision-making process should be based on the best interests of the child and should be in line with their level of maturity. While children will not be able to make autonomous decisions about their future, their right to express their opinion freely and to have that opinion taken into account in any matters affecting them, should be respected<sup>290</sup> and they should be enabled to participate meaningfully. The UN Guidelines for the Alternative Care of Children explicitly stress the need for full consultation with the child, according to their evolving capacities, at *all* stages of the decision-making process regarding the most appropriate form of care for them.<sup>291</sup>

<sup>290</sup> United Nations Convention on the Rights of the Child, Article 12.

<sup>291</sup> United Nations Guidelines for the Alternative Care of Children, paras. 6, 48, 56.



Adults are often reluctant to consult children because they are perceived to lack the competence and capacity to participate effectively. Nevertheless, even the youngest children have their likes and dislikes and can participate in issues that are important to them “[p]rovided that they are given appropriate support, adequate information, and are allowed to express themselves in ways that are meaningful to them – pictures, poems, drama, photographs, as well as conventional discussions, interviews and group work”.<sup>292</sup> Recently, the Council of Europe adopted a recommendation on the participation of children and young people under the age of 18, which explicitly states that “[t]here is no age limit on the right of the child or young person to express her or his views freely”.<sup>293</sup> A body of literature exists providing useful practical advice on communicating with very young children about significant changes in their lives. For example, Vera Fahlberg’s ‘A Child’s Journey Through Placement’.<sup>294</sup>

For young people leaving care, support should be available to prepare their transition to independent living. This process should involve the young person and be carefully planned. It should start well before the child is ready to leave their former care setting.<sup>295</sup>

### CASE STUDY 26: INVOLVING CHILDREN AND YOUNG PEOPLE IN THE PROCESS OF CHANGE

‘Children and young people in care – Discover your rights!’ is a booklet developed by the Council of Europe and SOS Children’s Villages International. It aims to give young people a better understanding of how alternative care works, what their rights are as a young person in care and whether these rights are being respected. The booklet also aims to help young people make decisions and improve their communication with their care givers and social workers.<sup>296</sup>

Lumos has worked with children and young people who have moved out of institutions (including children with intellectual disabilities) in the Czech Republic and Moldova to develop a series of interactive books for children of different ages and levels of understanding. The books help children to understand the deinstitutionalisation process, to prepare them for the changes that are coming, to record their concerns, wishes, hopes and memories and to find ways of saying goodbye.<sup>297</sup>

## 1.2 Involving children’s families

Where placement decisions are made regarding children, the involvement of families is essential. Often parents of children in institutions feel disempowered and defer to the professionals. In some countries, family-group conferencing has been introduced to ensure that parents and other family members can take an active and equal role in decision-making regarding children. It is often assumed that families who have placed their children in institutions, particularly where contact is rare or non-existent, do not want their children. However, in many countries, the authorities do not actively seek out families to ascertain the reason for their separation from their children.

292 Lansdown, G. (2001) *Promoting children’s participation in democratic decision-making*, Florence, Italy: UNICEF, Innocent research centre, p.8.

293 Recommendation CM/Rec(2012)2 of the Committee of Ministers to member States on the participation of children and young people under the age of 18 <https://wcd.coe.int/ViewDoc.jsp?id=1927229&Site=CM&BackColorInternet=C3C3C3&BackColorIntranet=EDB021BackColorLogged=F5D383>

294 Fahlberg, Vera (1991) *A child’s journey through placement*. Perspectives Press.

295 Eurochild *op. cit.* (2012a), p.17.

296 The booklet is available at: [http://www.coe.int/t/dg3/children/childrenincare/C&YP%20IN%20CARE-ANGLAIS\(web\).pdf](http://www.coe.int/t/dg3/children/childrenincare/C&YP%20IN%20CARE-ANGLAIS(web).pdf)

297 For more information about these interactive books for children, contact [info@lumos.org.uk](mailto:info@lumos.org.uk)





## CASE STUDY 27: ASSESSMENT OF FAMILIES IN BULGARIA

In Bulgaria, as part of the major deinstitutionalisation programme, the government organised a comprehensive assessment of 1,800 children with disabilities living in institutions and of their families. The assessment found that 53% of families wished to re-establish contact with their children, with a view to eventual reunification.

### 1.3 Adults

Adults should not only be consulted throughout the planning, implementation and monitoring process, they should also *be enabled to make decisions* about their lives, the support they need and how it will be provided. One of the core principles of the CRPD is “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”.<sup>298</sup>

However, older people and adults with disabilities are also often regarded as incapable of participating because of their age or the nature of their impairment, which may affect their intellect or speech. As with children, the provision of relevant support (primarily from their peers, combined with professional consultations when needed), information and assistance are key to enabling their effective participation. Thus, a person with a speech impairment would be able to participate if they had access to communication technologies or a support person who is trained in alternative and augmentative communication.<sup>299</sup> A person with an intellectual disability could be enabled to make decisions for themselves with the introduction of supported decision-making arrangements. Where the person cannot directly participate in the decision-making process, they could be represented by a trusted person. In this case the decisions made for or on behalf of the person should always be in their best interest.

## CASE STUDY 28: SUPPORTED DECISION-MAKING – EXAMPLE OF A ‘PERSONAL OMBUDSMAN’

Article 12 of the CRPD recognises that people with disabilities have legal capacity on an equal basis with others. It also acknowledges that some people may need additional support to exercise their legal capacity and requires Member States to adopt the necessary measures to ensure this support.

With supported decision-making, the person with disability is the decision maker.<sup>300</sup> The role of the supporter could be to explain the information to the person in an accessible way and help them understand the available options or to communicate the person’s preferences and opinion to the others. The supporter should listen carefully to the person and act in accordance with their wishes. They should respect the views and the choices of the person and should not substitute them with their own preferences. They should always represent the views of the person, even when they are in conflict with the view of the rest of the family or the support person themselves.

*(continues on next page)*

298 United Nations Convention on the Rights of Persons with Disabilities, Article 3 (a).

299 Inclusion International (2008) *Key elements of a system for supported decision-making*. Position paper.

300 United Nations, *op. cit.* (2007).





### CASE STUDY 28: *(continued from previous page)*

A good example of a service offering supported decision-making for users of psychiatry is the 'personal ombudsman' (personligt ombud), developed in Sweden after the psychiatric reform of 1995. A personal ombudsman (PO) is a professional, highly-skilled person dedicated exclusively to the service of the psychiatric patient. The PO is not in any alliance with psychiatry or the social services or any other authority and has no links with the patient's relatives or others in their surroundings. They assist individuals to take control of their own situation, identify care needs and ensure that they receive the necessary help. POs have no medical responsibility, nor do they make any decisions in an authoritative capacity; they work only to represent the individual.

In 2010, 325 POs were employed and provided support to more than 6,000 individuals throughout the country. In areas where POs work, there has been a significant drop in the number of suicides and drug abuse. People are less likely to be isolated or put under guardianship. Calculations also suggest that it reduces the costs of other services significantly.<sup>301</sup>

## 2. Individual assessment

Individual assessment, implementation and review are the main elements in the planning process. The purpose of the assessment is to provide detailed information about the person and their needs and preferences, which will inform the development of an individual support/care plan. The assessment should be linked to the strategy for the development of services, which means that the required support services need to be developed on the basis of the individual needs and preferences, rather than trying to fit the person into the existing options.

### 2.1 Framework and methodology

In the development of the methodology, both the specific country context and the particular user group should be considered. There is no right answer about what the methodology should look like, as long as it adheres to the following principles:

- **Involvement of users** and, where appropriate, of their families, carers or advocates, in decision-making about their future and support services. It is not possible to carry out an assessment simply by looking at the file and talking to the carers or professionals.
- **Meaningful participation throughout the whole process** by the families or advocates (as appropriate), including providing access to relevant support.
- **Holistic approach**, which takes into account the whole person, not only their impairment.
- **Consideration of an individual's strengths and resources**, in addition to their needs and the difficulties they face.

With regard to children, the UN Guidelines explicitly recommend that the assessment should be comprehensive and take into account both the immediate safety and well-being of the child and their long-term care and development. It also suggests some specific areas which the assessment should cover, including a child's "personal and developmental characteristics, ethnic, cultural,

<sup>301</sup> See [http://www.po-skane.org/The\\_Swedish\\_Personal\\_ombudsmen\\_system\(Maths\\_Comments\).php](http://www.po-skane.org/The_Swedish_Personal_ombudsmen_system(Maths_Comments).php)

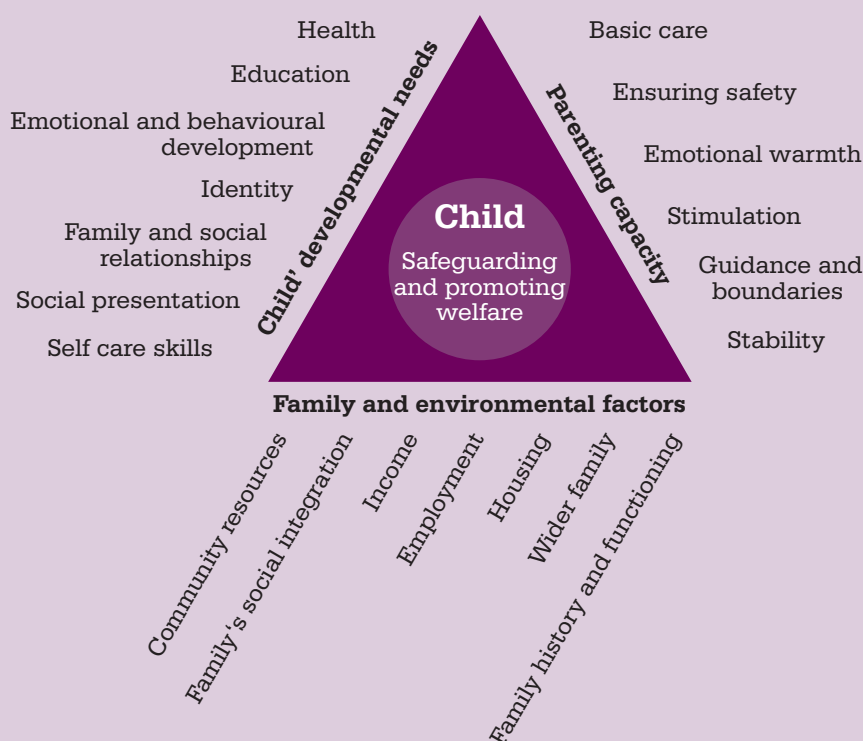


linguistic and religious background, family and social environment, medical history and any special needs".<sup>302</sup> With regard to children who have been institutionalised, the assessment should assess potential as well as current functioning. Care should be taken not to misdiagnose institutionalised children as autistic, since quasi-autistic behaviours are a common effect of institutionalisation and usually disappear once children have moved into family-based or family-type placements.

In relation to children, the main reference point is the full development of the child; this refers to the theories of child development as consisting of a series of stages, each with its own specific characteristics.

### CASE STUDY 29: EXAMPLE OF A COMPREHENSIVE ASSESSMENT FRAMEWORK USED IN THE CARE PLANNING, PLACEMENT AND CARE REVIEW FOR CHILDREN IN THE UK<sup>303</sup>

The assessment used in care planning in the UK draws on the more general Framework for the Assessment of Children in Need and their Families<sup>304</sup>, which identifies three inter-related systems of domains: the child's developmental needs, family and environmental factors and parenting capacity and a number of critical dimensions in each domain. Care planning is based particularly on the seven dimensions of developmental need.



302 United Nations Guidelines for the Alternative Care of Children, para. 57.

303 HM Government (2010) *The children Act 1989 Guidance and regulations. Volume 2: Care planning, placement and case review*.

304 Department of Health (2000) *Framework for the assessment of children in need and their families*, available at [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4014430.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4014430.pdf)



At an international level, there are no such specific recommendations about the focus of an assessment in relation to people with disabilities and older people. Nevertheless, the CRPD, the Madrid International Action Plan on Ageing and the UNECE Regional Implementation Strategy could be used as guidelines. These documents highlight the principles of inclusion and full participation of older people and people with disabilities in the political, social, economic and cultural life of the society. These principles should be the main reference point in the assessment and may highlight needs for support at home, at work, in health matters, in education and culture, in social relations and in leisure.

### CASE STUDY 30: THE SUPPORT INTENSITY SCALE (SIS) ASSESSMENT TOOL

SIS is an assessment tool used with people with intellectual disabilities to evaluate their individual practical support requirements. In contrast to traditional tools and approaches, which measure the skills an individual lacks, SIS focuses on the skills an individual possesses, evaluating the support needed for people to lead independent lives.

The tool measures support needs in the following areas: home living, community living, lifelong learning, employment, health and safety, social activities, protection and advocacy. Specific activities are defined in each area. For example, 'home living activities' include preparing food, eating food, housekeeping and cleaning, dressing, personal hygiene and housekeeping."<sup>305</sup>

The methodology may include tools that have been specifically developed for the purpose of the assessment as well as already existing instruments. In any case, it is the consistency of approach which is important, i.e. using the same tools for all children of the same age group or level of understanding.<sup>306</sup>

The existing tools could be used to guide the development of new instruments or could be applied directly. However in some areas (such as child development), there are a wide variety of instruments used for assessment of early childhood social and emotional development, such as the Denver scale.<sup>307</sup> They provide information only in a specific area, which means that they will not be sufficient for the development of individual plans and will need to be complemented by additional information.<sup>308</sup> The Support Intensity Scale, despite being very detailed with regard to individual needs, does not provide information about the family and informal relations of the person, which are important in the planning process.

## 2.2 Self-assessment

Self-assessment has emerged as the preferred option for ensuring that the support allocated to a person matches their real needs and requirements. It refers to a process whereby a person can assess their own care and support needs. If they wish, they can be supported by their carer, a

<sup>305</sup> For more information visit: [http://www.siswebsite.org/cs/product\\_info](http://www.siswebsite.org/cs/product_info)

<sup>306</sup> Mulheir, G. & Browne, K. *op. cit.*

<sup>307</sup> For overview of instruments for children 0–5 years, see <http://www.nectac.org/~pdfs/pubs/screening.pdf>

<sup>308</sup> Sosna, T. & Mastergeorge, A. (2005) *Compendium of screening tools for early childhood social-emotional development*. Sacramento: California Institute for Mental Health.





family member, a service provider, a peer or friend. Self-assessment is typically done through questionnaires, developed by the local (or other) authorities with the involvement of service users. It is very important to be aware that one type of questionnaire does not fit all, even of a single group of service users. The approach, the explanations and the questions need to be differentiated and adapted to each specific group and to its characteristics, for example migrant background, level of education or religion.

Peer support/counselling is a crucial part of a person feeling empowered and self-confident when approaching the self-assessment process. It is only peers who, by sharing experience and raising awareness of the person being assessed, can help identify real needs. It is often that people see their daily life in minimalistic terms – just personal hygiene, dressing and eating. It is the peer's job to challenge such minimalistic expectations of the person to help them see additional opportunities to participate. The peer-to-peer nature of the relationship can be more persuasive than the expert-client one.

## 2.3 Preparing and conducting the assessment

The individual needs assessment could be conducted by professional/s or the individual themselves. When the assessment involves interaction between a professional and a user, careful preparation is required. For example, prior to the assessment, the professional or the team conducting the assessment should review the available information and, if needed, meet with the relevant personnel member for further discussions.<sup>309</sup> Special attention should be paid to ensuring that all the support needed to enable the person to participate meaningfully in the assessment and planning process is in place.

For a number of reasons, the assessment can be a stressful experience for both children and adults, so some effort is required in order to make the person feel comfortable. Depending on the situation, this may be achieved by carefully explaining the purpose of the assessment and/or by inviting someone familiar to the person to be present. The potential for stress is also why self-assessment (which involves a person doing the assessment in their own time and their home environment) is a recommended option. Assessments of young children should take place through specific play activities.

Special attention should be paid to overcoming communication barriers. Some people may find it difficult to communicate using only speech. However they can still express their wishes and preferences using different methods of communication – facial expressions, gestures, symbols and pictures or writing.<sup>310</sup> For meaningful participation of these users in the assessment and planning process, the person's specific method of communication must be known and understood.

<sup>309</sup> Mulheir, G. & Browne, K. *op. cit.*

<sup>310</sup> See Augmentative and Alternative Communication, at: <http://www.asha.org/public/speech/disorders/aac.htm>





### CASE STUDY 31: PERSON-CENTRED APPROACHES TO PLANNING

The term 'person centred planning' (PCP) refers to a range of approaches to planning based on the principles of inclusion.<sup>311</sup> Some of the most common planning styles in PCP include: Essential Lifestyle Planning, developed initially for people returning to their home communities from institutions and residential schools; PATHS (Planning Alternative Tomorrow with Hope); MAPS (Making Action Plans); and Personal Futures Planning.

In recent years PCP has increasingly been used in the planning of care and support for young people, adults and older people. An individual's own person-centred plan could be used in the formal assessment, in the development of an individual care and support plan linking individuals and families with public services and in the review process.

One of the distinctive characteristics of PCP is that it focuses on the person's aspirations. The planning process begins by exploring what is important for the person in the present and goes on to building a vision of the desired future which is based on their capacities and resources rather than on deficits and needs. The last step is the development of an action-plan. This is where the vision of the future is turned into clear goals, with specific steps for achievement and with specific responsibilities being assigned to the people involved in the planning. This is another important feature of the person-centred approaches: the family members and the wider social network are actively involved in the planning process, becoming the person's 'circle of support'. They participate in the planning itself, can take on specific responsibilities in the implementation of the plan and usually continue to support the person after the planning process is completed.

## 3. Individual care and support plan

The plan will provide information about the placement and living arrangements, as well as the additional support that will be provided to the person and (where necessary) their family or carers. It will formulate clear goals, as well as specific and measurable outcomes. The timeframe and responsibilities for its implementation also need to be specified. It should set out the views of the person and their family, demonstrate how they were considered in the planning process and how they were reflected in the plan.

### 3.1 Children

The best interests of the child, their safety and security should be the main consideration in deciding the most appropriate form of care (for different alternative care options see Chapter 5). In addition, the following principles should be considered:<sup>312</sup>

- **Removal from family is a last resort:** Removal of a child from the care of the family should be seen as a measure of last resort. Whenever possible, it should be temporary and short-lived.
- **Contact with the family:** The placement should allow the child to live as close as possible to their home in order to encourage contact with their family (except in cases where this is not in the best interest of the child) and to avoid disruption in educational, cultural and social life.

<sup>311</sup> See, for example, UK Department of Health, *Personalisation through Person-Centred Planning*, at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_115175](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115175)

<sup>312</sup> United Nations Guidelines for the Alternative Care of Children.



- **Reintegration as the first option:** In cases when the child has been separated from their family and placed in alternative care, their possible reintegration should be prioritised over all other measures. Alternative care should be provided only when the family is unable, even with appropriate support, to provide adequate care for the child or where it is unsafe for the child to return to their family.
- **Family-based care for children under three years old:** Alternative care for young children, especially those under the age of three, should be provided in family-based settings.
- **Residential setting if necessary and appropriate:** Residential care should be limited to cases where such a setting is appropriate, necessary and constructive for the individual child concerned and is in their best interests.
- **Siblings should not be separated:** Siblings should not be separated by placements in alternative care and should be able to live together (unless an assessment identifies that separation is explicitly in their best interests). Children placed in institutions are often separated from their siblings. Therefore, in the transition phase, one of the goals should be to enable siblings to live together.
- **Permanency:** Frequent changes in the care setting are detrimental to the child's development and ability to form attachments and should be avoided. Short-term placements should aim to enable an appropriate permanent solution.

### 3.2 Adults

Adults should be given the assistance they need to make an informed decision about where they want to live and how their support should be organised. As set out in the CRPD, people with disabilities should “have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and [should not be] obliged to live in a particular living arrangement”.<sup>313</sup> This means that countries have a responsibility to provide a range of support services, including variety of housing arrangements, which will give people with disabilities and older people a genuine choice.

<sup>313</sup> United Nations Convention on the Rights of Persons with Disabilities, Article 19 (a).



### CASE STUDY 32: ROLE OF THE MENTAL CAPACITY ACT (ENGLAND AND WALES) IN DECISION-MAKING ABOUT SUPPORT AND LIVING ARRANGEMENTS

In the UK, the Mental Capacity Act formulates the following statutory principles to protect people who lack the capacity to make particular decisions, while at the same time maximise their ability to make decisions and to participate in decision-making.<sup>314</sup>

In the decision-making process about support and living arrangements, the following principles need to be observed:

- A person must be assumed to have capacity unless it is established that they lack capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- Before the act is done, or the decision is made, consideration must be given to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.<sup>315</sup>

## 3.3 Reviewing the plan

The review of the individual care and support plan is an important part of the planning process. Its purpose is to monitor the progress towards the outcomes set out in the plan and to make necessary amendments, taking into consideration the new information and the changed circumstances. The review of the plan for children in alternative care will help determine the adequacy and necessity of the placement in the light of the child's personal development and the development in their family environment.<sup>316</sup>

The frequency at which care and support plan reviews take place should be legally regulated and will depend primarily on individual circumstances. Users should be able to request a review of their plan when there is a change in circumstances.

## 4. Challenges in the planning process

### 4.1 'Cookie-cutter' approach<sup>317</sup>

Some institutional closures have been characterised by a 'cookie-cutter' approach in which service models, such as group homes, are imposed, with individuals being placed according to the perceived needs of a group. While this approach may be appealing and may appear to be efficient in the short term, the resulting living arrangements usually fail to meet the needs of individuals and can lead to problems (such as institutional service delivery or interpersonal conflicts) and inefficiencies (multiple moves or additional professional interventions).

<sup>314</sup> In the view of Mental Health Europe, this legislation is considered as one of the most advanced mental health acts in Europe. However, they also pointed out that the Mental Capacity Act for England and Wales has met some criticism from organisations of (ex-)users of psychiatry for its paternalistic approach.

<sup>315</sup> Department for Constitutional Affairs (2007) Mental Capacity Act 2005 Code of Practice, London: TSO, p.19. Available at <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf>

<sup>316</sup> United Nations Guidelines for the Alternative Care of Children, para. 66.

<sup>317</sup> People First of Canada/Canadian Association for Community Living *op. cit.*, p.10.



This risk can be avoided by ensuring that planning is person-centred and individualised. Each person should be empowered to make a decision about where and with whom they want to live, so that the resulting arrangement is truly their home.

## 4.2 Effects of institutionalisation

Decision-making could be challenging for people who have spent a long time in an institution. After leaving an environment with rigid daily routines and rules and which is dominated by paternalistic relationships<sup>318</sup>, the person may find it difficult to formulate and express their preferences and to make autonomous decisions. At the same time, prolonged isolation from the community (since birth, for some) will make it very difficult for a person to imagine life outside of the institution and to identify what support they might need.

It is therefore crucial that during the planning process people have access to information, advice and support on independent living. Support from other people with disabilities who already live independently (having experienced institutional care) and who can act as role models is crucial in this process. They can share their experience about what it is like to live independently in the community, about the challenges that they are facing and the solutions that they have found. In this process, the person not only gains useful information, they can also become more confident in their ability to live independently in the community and feel empowered to do so.

Even if currently there are few options for community support available, contact with other people who live independently could be empowering for the person. Equally, parents of young adults who are about to move out of the institution might find it reassuring to hear experiences of others in a similar situation as their child.

### TESTIMONIAL 4: JOSÉ'S STORY<sup>319</sup>

José moved into a long-stay residential institution when he was 18, after finishing high school because he did not want to be a burden to his family. This placement was offered to him by the municipality and there were 55 other people living there.

Even though he soon realised he wanted to leave, José ended up living in the institution for 12 years. As he was trying to find ways to move out, he went to different seminars in his town organised by other disabled people and supported by the regional authorities. There he met with independent living activists who told him about the Independent Living philosophy. What motivated José to leave was one disabled activist telling him: If I can do it, you can. He was also the one who continued supporting José after leaving the institution.

José managed to find a job at a local hotel and has been able to stay there. He is still finding different ways of getting personal assistance (which is not an entitlement in his country) and other support. It is not easy, but he is happy to be out of the institution. His family was not convinced that living independently was the right solution for him, but he said that, as his mother met more “crazy” people like him, she started to believe he could do it too.

José pointed out that in his experience even open institutions, such as the one where he spent 12 years, do not work. Although he was able to leave the institution during the day, he felt humiliated by the staff. They told him he was useless because he could not do anything by himself, and treated him like a child.

In José's words, “if a system does not empower people, it cannot work”.

<sup>318</sup> Ad Hoc Expert Group Report.

<sup>319</sup> Obtained with Jose's permission from the European Network on Independent Living (ENIL).



Helping children get ready to move from institutions often begins with assisting them in learning to make basic choices, such as what to eat, which play activity to choose and who they want to play with. Gradually more and more complex choices are introduced, until they are able to cope with complex decision making related to their future care.

### 4.3 Medicalisation

Often, the individual assessment of people with disabilities or frail older persons focuses predominantly or exclusively on their health and medical condition, which is seen as *the* source of their problems (the medical model of disability). Consequently, this leads to a plan which contains mainly medical and corrective measures. Another aspect of medicalisation is the emphasis in the plan on 'special arrangements', such as special schools.

The purely medical approach to understanding and defining the needs of people with mental health problems is also highly problematic and can lead to human rights abuses. In addition to providing temporary or long-term support to mental health service users, medication can be a tool for 'chemical detention', which only substitutes real support and help.

In order to avoid medicalisation, assessments should be holistic, based on the 'social model of disability' and ageing, as well as on the human rights approach to disability and age. This will involve recognising that barriers in the environment are the main factor in disabling people (social model of disability) and that all people with disabilities and older persons should be entitled to full and equal participation in every aspect of society.

Even though mental health services often focus exclusively on pharmacotherapy, international standards call for the provision of a broad range of therapies, including: occupational and group therapy, individual psychotherapy, art, drama, music and sports, access to recreation rooms and outdoor exercise, as well as educational and employment opportunities to enhance independence and functioning.<sup>320</sup>

#### CASE STUDY 33: THE OPEN DIALOGUE TREATMENT, FINLAND

The Open Dialogue Treatment<sup>321</sup> is a method for helping people who have been diagnosed with psychosis. It has been found to be especially effective when used early in a crisis. The main characteristics of this treatment are that it has the best reported recovery rates for people diagnosed with psychosis. In most cases it does not involve antipsychotic drugs; it involves service users and families in all key decisions; offers immediate, flexible and individualised help and values diversity of voices and perspectives.

As soon as a person begins to experience the symptoms of psychotic disorder, a team of professionals brings together as many people from this person's life as they can. They meet on a daily basis or every other day for two or three weeks. During the meetings, the professionals create a safe environment in which everyone is encouraged to tell their stories – stories about themselves, the patient and the family.

This method has resulted in a steep drop in the in both the number of days spent in hospital and the amount of neuroleptics prescribed. Ongoing research shows that over 80% of those treated using this method return to work and over 75% show no residual signs of psychosis.

320 8<sup>th</sup> General Report of the Committee for the Prevention of Torture, para. 37, available at: <http://www.cpt.coe.int/en/annual/rep-08.htm>

321 On the outcomes of the Open Dialogue Method, see: Jaako Seikkula et al., Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. Published in *Psychotherapy Research*, March 2006; 16(2):214–228.



**Table 6: An illustration of the differences between the medical and the social model**

	Medical model	Social model
<b>Main assumption</b>	The person is disabled by their impairment	The person is disabled by the barriers in the environment
<b>Assessment</b>	Focused on medical problem, individual deficits and lacks	Focused on barriers in the environment; identifies support needs
<b>Suggested solutions</b>	Fixing individual weaknesses, institutionalisation, segregation	Fixing the environment; inclusion

#### Examples<sup>322</sup>

	Medical model	Social model
<b>Problem</b>	Unable to do the household work because cannot use hands	Unable to do the household work because of lacking technical and social assistance
<b>Solution</b>	Institutional care, rehabilitation, medical interventions	Technical aids, personal assistance, in-house support services.
<b>Problem</b>	Unable to understand complex written text because of learning difficulties	Texts are not available in plain language and easy-to-read format
<b>Solution</b>	Special school, residential institution	Text in easy-to-read format; resource teachers, personal assistance, inclusive education

## Further reading

Beresford, P. & Croft, S. (1993) *Citizen involvement: a practical guide for change*, London: Macmillan.

Cullen, S. (2005) *Involving users in supported housing: a good practice guide*, London: Shelter.

Department of Health (2008) *Real involvement: Working with people to improve health services*.

Goldbart, J. & Caton, S. (2010) *Communication and people with the most complex needs: What works and why this is essential*. London: Mencap.

Hasler, F. (2003) *User at the heart: User participation in the governance and operations of social care regulatory bodies*. London: Social care Institute for Excellence.

Sanderson, H. (2000) *Person centred planning: Key features and approaches*. London: JRF.

SOS Children's Villages International and Council of Europe (2009) *Children and young people in care. Discover your rights!* Strasbourg: Council of Europe.

<sup>322</sup> Based on European Coalition for Community Living (2008) *Creating successful campaigns for community living – Advocacy manual for disability organisations and service providers*.



## CHAPTER 8: SUPPORTING INDIVIDUALS AND COMMUNITIES DURING TRANSITION

*The transition to the community is not simply about physically moving people from an institution to their new place of living or care placement. In order to avoid re-institutionalisation and to ensure the best possible outcomes for the people using the services, the move to the new living arrangement should be planned with care.*

*This chapter shares ideas about how this transition process could be prepared for and supported. It also highlights the importance of working with carers and communities.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

Persons with disabilities must be provided with accessible information about the assistance, support services and facilities available to them (Article 4). In addition, State Parties have an obligation to raise awareness at different levels – at a societal and at a family level – with the objective of fostering respect for the rights and dignity of persons with disabilities. These measures should seek to “combat stereo-types, prejudices and harmful practices”, “promote awareness of the capabilities and contributions of persons with disabilities” and should be done through the schools, the media, public awareness raising campaigns and training programmes (Article 8).

## 1. Supporting the service users

The transition from institutional care to life in the community is an enormous change for the person leaving the institution, whether they are a child, a young person leaving care, an adult or an older person. The whole life of the person changes: where and with whom they live, who looks after them or provides support, who their friends and neighbours are and even how they eat and dress. Unless it is carefully planned and implemented, this transition has the potential to be a very stressful and traumatic experience which could have damaging consequences for some individuals.

It is crucial that the process of transition to independent and community living is in line with the individual plan and takes individual preferences into account.

### 1.1 Planned and gradual transition

Whenever possible, the closure of an institution and transition to the community should be implemented as part of a planned process towards development of community-based alternatives in order to achieve the best possible outcomes for the residents. There will be cases, however, when the closure and move of the residents will be implemented in an emergency manner with less time for preparation. For example, financial problems experienced by the provider may lead to the need for urgent closure. Urgent measures will also be required when there are concerns about the quality or the safety of the services. Relevant child protection and adult protection policies need to be in place to assist in situations when there is a risk of harm for the person – a child or a vulnerable adult.<sup>323</sup>

<sup>323</sup> For additional information see Department for Children, Schools, and Families (2010) *Working together to safeguard children*, available at <https://www.education.gov.uk/publications/eOrderingDownload/00305-2010DOM-EN.pdf>; and Department of Health and Home Office (2000), *op. cit.*







### 1.1.1 Children

If there is no immediate danger of harm, the transition of the child from the institution to the new setting, or back to the family of origin, should be a gradual process.

Once the most appropriate care option has been identified, a detailed plan needs to be developed outlining the different steps in the transition process. It should provide information about: activities, expected outcomes, location of the activity, time (when it will happen and how long it will last), the person responsible and other relevant information. However, the plan should not be rigid; the professionals working with the child during the transition process should keep the plan under continuous review, making changes as necessary and with the full knowledge and participation of the child.

As a whole, the purpose of the transition period is to familiarise the child with their new environment and to support them in building an attachment with the parent or carer who has taken over the primary responsibility of care. The healthy attachment is seen as particularly important in the first years of the development of the child.<sup>324</sup> Examples exist of tried and tested transition preparation programmes for children of different ages and stages of development and with different needs.<sup>325</sup>

Activities in the first stages of the preparation period will usually be organised in an environment familiar to the child (usually the current placement) and, if needed, in the presence of a trusted person. When the child feels comfortable enough with their parent or carer, visits to their home could be arranged. Initially, they will be short and the child may be accompanied by a trusted person from the previous care setting; gradually their length could increase to overnight stays. The actual physical move of the child to the new place should only take place in line with their individual plan and preferences. The necessary support should be provided after the transition process is completed.

The preparatory process involves not only the child, but all other people concerned with the new placement, for example:

- **the parents (birth, adoptive or foster parents):** Parents may need information as well as consultation, training and advice before, during and after the transition in order to be able to build good relationships with the child and to provide better care (see ‘Supporting carers’, below);
- **other children:** If the child is going to live with other children, for example in a group home, they need to be informed as well and engaged as much as possible in welcoming the child. In cases of reintegration, a child’s siblings should receive special attention and preparation as well; and
- **the personnel at the new placement:** If the child is going to live in a residential setting, such as a group home, the personnel will need to receive all the necessary information about, *inter alia*, the child’s history, care needs and interests, etc.

### 1.1.2 Young people leaving care

The term ‘leaving care’ refers to situations when a child is integrated into their family (biological and/or extended) or when they reach maturity (typically 18 years of age) and are considered ready to live independently. It is a crucial time for young people in alternative care and failures to provide adequate and ongoing support can have devastating consequences. They can lead to re-

<sup>324</sup> According to “attachment theory”, children raised in institutions have limited opportunities to form an attachment, which is seen as the cause of many emotional, behaviour and cognitive problems. See Fahlberg, Vera, *op. cit.*

<sup>325</sup> For examples of preparation programmes, see Mulheir, G. & Browne, K. *op. cit.*, p.85.







institutionalisation and the need for other adult residential services, such as psychiatric hospitals or prisons, as well as homelessness, criminality and prostitution.

Therefore, it is crucial that for children and young people leaving care, support is available to prepare their transition to independent living. The support provided should include, for example, training in how to organise and manage the household as well as skills related to budgeting and managing money. Practical support with personal documents, bank accounts and housing should also be provided. Equally important is the psychological support, focusing on the development of self-esteem and the ability to build and maintain personal relationships. Vocational training should also be offered. Evidence shows that access to such preparation programmes and the quality of preparation vary greatly within and across countries, suggesting that not all young people are adequately prepared for adulthood.<sup>326</sup>

Recommendations on how to support children and young people leaving care are set out in the **UN Guidelines on the Alternative Care of Children** (paragraphs 131–136) and **Quality 4 Children Standards** (15–18).

### 1.1.3 Adults

The transition of adults with disabilities and older people also needs to be gradual and carefully prepared with special attention and support provided to those who are most vulnerable. For example, older people normally move into institutions at a later stage in their lives when permanent changes in living and caring conditions become more and more difficult to accept and to manage psychologically. Therefore every effort should be made to reduce stress and support the person throughout the transition process.

As with children, an important part of the preparation could be to familiarise the person with their new environment and people and to establish relationships. For example, if the person is moving to a staffed living arrangement, this may involve the personnel from the new setting visiting the person in the institution and establishing relationships. Later, it could include visits from the service user to the new setting, perhaps with someone they trust. The stress from the change could also be reduced by moving as much as possible of the resident's furniture and personal belongings to the new place and by keeping together key members of personnel and residents (e.g. by hiring personnel members in new service), where this is both possible and in the best interests of the person.

When planning the transition it is also important to give an opportunity to groups of friends to stay together or to remain in contact by, for example, making the necessary transport arrangements.

<sup>326</sup> Lerch, V. & Stein, M. (eds.) (2010) *Ageing Out of Care: From care to adulthood in European and Central Asian societies*, SOS Children's Villages International, Innsbruck, Austria, p.132.





### TESTIMONIAL 5: PROTECTING FRIENDSHIPS BEYOND INSTITUTIONAL LIFE

“When moving people from the institutions we must protect their friendships. I have seen many people lose their friends when they leave the institution. They are sent to different towns and cities. They move to different homes and other places to live. We must remember that these people do not drive a car; they do not know how to catch a bus or a train. They usually cannot write and email is a word other people use. We must also remember that some of these friendships have been made over the many years we were locked away. They are very important to us. What we need is awareness and good support to ensure these friendships continue.”<sup>327</sup>

## 1.2 Independent living and daily living skills

Some people living in institutions have not had an opportunity to develop the basic skills necessary to run their everyday lives or have lost them as a consequence of institutionalisation. Therefore it is helpful, before they leave the institution, to assist them in developing daily living skills. This may involve, for example, training in home management skills, such as cooking, cleaning, laundering, ironing, washing dishes, etc., maintaining personal hygiene, dealing with money and shopping, using public transportation and public services, safety and establishing social relationships. However, the degree to which different people will be able to develop such skills will vary. Therefore, access to a wide range of community-based support services, such as home help and care, should also be provided.

Other people may benefit from training and advice related to personal assistance as a key to their independence. This might include information and support to help decide which is the best way for them to organise a service (such as through a service provider, user-cooperative or by themselves), or training on how to assess their needs or how to recruit and manage their assistants. Many people will find it difficult to take an active role in their relationships with the assistant or the service provider, and additional support will be essential for this. The support should be based on the principle of independent living, grounded in the social model of disability and provided by peers.

<sup>327</sup> Martin, Robert (2006) “*A Life Worth Living*”, speech given to the Inclusion International World Congress in Mexico, November 2006, published in *Self-advocacy Toolkit*, Inclusion International. Available at: [http://www.inclusion-international.org/wp-content/uploads/Annex\\_B-Working\\_with\\_Self\\_Advocates-Toolkit2.pdf](http://www.inclusion-international.org/wp-content/uploads/Annex_B-Working_with_Self_Advocates-Toolkit2.pdf)





### TESTIMONIAL 6: CIARA'S THOUGHTS ON LIVING INDEPENDENTLY<sup>328</sup>

It is important for me to live independently, because I want to have a good life like anyone else.

A few years ago I lived on my own in my first flat. I liked having a flat of my own, but I found it hard.

Now, I live with my fiancé Mark in a two bedroom rented flat in Surrey.

We have lived there together since June 2009. We looked for a flat through a local estate agent. I was really happy when I was given my keys for the flat.

I think that living independently is important because I can have friends and family over to visit me when I want.

I like to prepare and cook meals for myself. I have some easy instruction cook books at home so that I can learn to make healthy meals.

When we receive bills in the post, Mark and I look at them and we make sure that we read them carefully.

If I don't understand what they are about, then Mark helps me to understand.

I have learnt to budget my money so that I can pay my part of our bills and rent and I pay my mobile phone bill every month.

I clean my flat so it is nice and tidy. I do my own laundry so that I can have clean clothes to wear every day.

I go to the local library down our road to rent out books and DVDs. I also go to the local leisure centre to go and have a swim.

On Monday nights I also go to a local Zumba dance class. It is held at a local venue near to my flat so I can walk there and back on my own. My class is £5.00 a week.

I enjoy living independently. I get to live my life the way I want to, make my own choices, have dinner when I want to have dinner, go out and come in whenever I want!

I love it!

For others, however, it may be important to know how to prevent crisis situations and to develop effective coping strategies in order to deal with them.

Sometimes independent living skills are developed in so-called 'half-way houses' built in the grounds or in the vicinity of the institution. While this is meant to be a temporary placement, these homes can turn into mini-institutions, with residents remaining there indefinitely. It is therefore advisable to invest resources in other forms of support. Where half-way houses exist, it is important to ensure that they provide a temporary, short-term placement, and that they are a stepping stone to independent living.

<sup>328</sup> Taken with Ciara's permission from Inclusion International's Global Campaign on Article 19. For more information, see: <http://www.ii-livinginthecommunity.org/page19.html>





### CASE STUDY 34: WELLNESS RECOVERY ACTION PLAN (WRAP®)<sup>329</sup>

WRAP is a self-help tool, developed by mental health service users, to help individuals take more control over their own wellbeing and recovery. It is based on the premise that there are no limits to recovery: “people who experience mental health difficulties get well, stay well and go on to meet their life dreams and goals”. It emphasises that people are the experts in their own experience and highlights the importance of self-advocacy, education and support. WRAP shifts the focus in mental health care from “symptom control” to prevention and recovery.

WRAP is developed on the basis of a careful observation of one’s experience and includes:

- things the person needs to do every day to keep themselves well, such as eating three healthy meals and getting a half-hour of exercise;
- external events that could trigger symptoms or a distressing experience, such as an argument with a friend or getting a big bill;
- wellness tools that might keep this event from making the person feel worse, such as a list of things one has done in the past (or could do) to help them stay well;
- early warning signs, such as irritability or anxiety, that indicate one might be starting to feel bad, together with a response plan; and
- signs that indicate the situation is getting much worse, such as reckless behaviour or isolation, and an action plan to stabilise the situation.

It can also involve the development of a personal crisis plan to be used when the person needs others to take over responsibility for their care. The plan will include:

- a list of supporters, their roles in the person’s life and their phone numbers;
- a list of all medications the person is using and information on why they are being used;
- signs that let the supporters know they need to make decisions for the person and take over responsibility for their care; and
- instructions that tell the supporters what the person wants them to do.

## 1.3 Self-advocacy

An important part of the transition from institutional care to living in the community is the support and promotion of self-advocacy. Self-advocacy means that people with disabilities and older persons are enabled to speak up for themselves and have control over their lives. Children and young people in care should also be encouraged and supported to express their views and “their voices and experiences should be heard, valued and used to inform policy and action”.<sup>330</sup>

Becoming a self-advocate may involve support with making decisions. Many people with intellectual disabilities, for example, lack decision-making abilities and skills because they have never been allowed to decide for themselves. However, everyone can learn how to make decisions with support from family members, other people with disabilities, carers and friends.

For other people, becoming a self-advocate may require coaching to become more assertive. In addition, provision of relevant information (e.g. regarding legal rights), building practical skills for self-advocacy (e.g. running or participating in meetings, or public speaking) and involvement in self-

<sup>329</sup> Based on <http://www.mentalhealthrecovery.com>.

<sup>330</sup> Eurochild *op. cit.* (2012a) p.18.





advocacy groups may also be important. In all these activities, the role of organisations of young people, people with disabilities and older people should be central.

## 1.4 Peer support

Organisations of children with experience of the care system, people with disabilities and older people should be actively involved in supporting the transition of users to the community. Depending on their capacity, they might be able to provide training on independent living skills, to offer individual counselling or participation in peer-support groups, to include the person in a self-advocacy group or to provide information.

The term 'peer support' refers to "people with a particular experience or background advising and supporting others in a similar situation".<sup>331</sup> Peer support has been defined as one of the core services for independent living by the pioneers of the disability independent living movement<sup>332</sup> and it is equally important for children and older people. Its value lies in the equal relations and the unique experience and knowledge of the people involved. Thus, one organisation of people with mental health problems engaged in advocacy and self-advocacy stresses that: "we have an intimate understanding of the needs of people who seek mental health services. We have personal experience navigating the bureaucratic maze of the mental health and other public systems and act as role models who teach people from a practical perspective how to understand and exercise their legal rights."<sup>333</sup>

Peer-support could play an important role in the process of transition from institutional care to community living as well as afterwards. It could be provided in different locations and in different formats, such as individual or group. There are also different types of peer-support, for example mentoring (which is more task-focused), or befriending (which is focused on supportive relationships).

## 2. Supporting carers

Families that will be caring for their children, older parents or other relatives leaving the institution should receive information and, where needed, additional training and support in order to provide better care.

For example, key to the success of a foster placement is training and support to foster carers in understanding the effects of abuse and attachment disorders on the child's emotions and behaviour, in addition to the provision of strategies for supporting the child. In the absence of quality support and learning, carers will often personalise the situation and give up, feeling that they are not doing well enough. Placement breakdowns will further traumatise the child. Therefore, it is essential that carers have the knowledge and skills to meet the immediate needs of the person in terms of physical and emotional well-being. However, it is also important that they are familiar with the principles and practices of independent living and inclusion and that they know how to empower someone to live a full life.

The needs of informal carers themselves should also be addressed. The lack of support for carers can result in stress and burn-out, which may have a negative effect on their health<sup>334</sup> and that of the person they care for, sometimes leading to their re-institutionalisation. Families can also

331 NCIL (2008) Peer support and personalisation, [www.ncil.org.uk/imageuploads/Peer%20support%20Final%201.doc](http://www.ncil.org.uk/imageuploads/Peer%20support%20Final%201.doc)

332 Evans, J. (2001) *Independent Living and Centres for Independent Living as an alternative to institutions*.

333 See Disability Rights California, at: <http://www.disabilityrightsca.org/about/psa.htm>

334 World Health Organisation & World Bank, *op. cit.*, p.150.





suffer from social isolation as a result of the stigma towards children, adults with disabilities<sup>335</sup> and the aged. They therefore need to receive assistance to assess their needs and should be given comprehensive information about available support services for carers in the community.

Services that could give the carers a break from their responsibilities are also important. Full-time care is usually very exhausting and challenging, physically and emotionally, for the carer, who might sometimes be an older person themselves. Consequently, it is very important to arrange for substantial recreation time for the carer in order to protect them as much as the person cared for. Holidays, which provide replacement care by trustworthy external carers, need to be provided systematically.

### CASE STUDY 35: EXAMPLES OF SUPPORT FOR CARERS

In 2010, twelve carer organisations (mainly family carers) took part in the Grundtvig Learning Partnership 'Self-assessment of their needs by family carers: The pathway to support'. The objective of the partnership was to:

- identify good practice; and
- support the development of tools for awareness-raising and training to promote self-assessment of their needs by family carers.

The project produced general and specific recommendations for the development of a Family Carer Self-Assessment Tool that should provide a comprehensive framework to examine all of the family carer's physical, mental, psychological, social and financial needs. Such a tool should help family carers identify and express their needs and ensure that every effort is made to support them.<sup>336</sup>

In France, Adapei 44, a local association for people with intellectual disabilities and their families, offers SAFE, an education support outreach service for parents and other non-professionals caring for a child with an intellectual disability. SAFE is a psychologist-run service that intervenes where there are communication difficulties with the child or challenging behaviour. They work with the family to assess its needs in relation to the child's education and to set up educational strategies. This early intervention service contributes to raising awareness of the role of family carers. It helps family carers voice and address their needs, is a source of information and acts as a gateway to other forms of support.<sup>337</sup>

In Ireland, The Carers Association offers a confidential, friendly and supportive national Care Line: 1800 24 07 24. This free listening service is a vital link for the isolated carer. Staff are able to refer callers to their closest Resource Centre, find information for them, advise them on rights, entitlements and benefits or just chat with carers in a supportive, understanding and non-judgemental way. Staff can ask carers if they would like to continue to receive information and support from the Association and thereby initiate a longer term relationship. The Care Line often receives calls from carers who are at a crisis point and so is invaluable in supporting them at times of difficulty.<sup>338</sup>

A number of countries have introduced legislative changes to protect informal carers and regulate their working situation and employment conditions. The case studies of Spain, Germany and Slovakia can be accessed through the INTERLINKS project.<sup>339</sup>

335 Mencap (2001) *No ordinary life*, London: Mencap.

336 Grundtvig Learning Partnership, *op. cit.*

337 *Ibid.*

338 *Ibid.*, p.12.

339 For more information about the situation in Spain, see <http://interlinks.euro.centre.org/model/example/SpecialCollectiveAgreementForInformalCarers>; for Germany, see <http://interlinks.euro.centre.org/model/example/CareLeaveAct>; for Slovakia, see <http://interlinks.euro.centre.org/model/example/SocialProtectionOfInformalCarers>





### 3. Working with communities

Work with communities<sup>340</sup> is an essential part of the deinstitutionalisation process. Negative attitudes and prejudice towards children who have lived in care, people with mental health problems and people with disabilities in general, as well as older people, can hamper the development of community-based services. The case study below is an illustration of this. Once deinstitutionalisation is underway, stigma will hinder full inclusion and participation in the community and can even lead to discrimination and violence.

#### CASE STUDY 36: NEGATIVE ATTITUDES TOWARDS PEOPLE LEAVING INSTITUTIONS

In one community, the decision to build group homes for children with intellectual disabilities leaving a residential institution was met with a fierce opposition from people living in the neighbourhood where the houses were supposed to be located. More than 400 signatures were collected in one day and hundreds of people took to the streets to protest against the decision.

The arguments of the protesters clearly showed the widespread myths and negative attitudes towards people with disabilities. Some mothers explained that they did not want their “healthy” children to play with the “sick” ones and that just seeing disabled children would be distressing for the other children. Other people said they have heard that these children scream and shout all the time and could be heard from 30–40 meters.<sup>341</sup>

Canada is one of the countries to have carried out successful community inclusion work, with five factors identified as leading to successful inclusion. The first is to establish ‘community building’ as the foundation of inclusion. Under this objective, community inclusion is “framed as having benefits to the community at large, not simply to people with disabilities and their families”. It highlights the need to “identify and underscore the reciprocal benefits for all partners when communities become more inclusive. (For instance, effective, inclusive schools and early child development programs are better programs for all children; inclusive businesses tap into broader markets and yield reputation benefits; inclusive municipal services better meet the needs of all local citizens and inclusive community recreation programs will find ways of making programs relevant to a broader base of participants)”.

Community inclusion work is about addressing the ways in which many communities experience additional barriers to inclusion due to their particular status, such as women, immigrants, young families, youth, older people, poor individuals and families.<sup>342</sup>

Therefore, as part of the process of deinstitutionalisation, special attention should be paid to the planning and implementation of awareness-raising activities aimed at overcoming resistance to community-based services and at ensuring the full inclusion of people leaving institutions. Promoting dispersed housing should also help, since it prevents the ghettoisation of people with disabilities (children and adults) or older people within the communities. It makes it easier for communities to see people as individuals and accept them as their neighbours.

340 By “community” we mean ordinary neighborhoods where people live, interact, do business, etc.

341 Stadart, “Rousse Citizens Divide Over Mogilino Children Placement”, 7 March 2012, see: <http://paper.standartnews.com/en/article.php?d=2012-03-07&article=16971>

342 Taken from the policy document “Factors that have led to successful inclusion in communities” (Canada).





It is important to work directly with local communities to address their fears, as well as to implement local, regional or national media campaigns to promote independent living and the values of inclusion. Organisations of people with disabilities and parents can be a valuable resource in the preparation and the implementation of such campaigns.

### KEY GUIDANCE 11: LESSONS LEARNED FROM WORKING WITH COMMUNITIES<sup>343</sup>

- Person-centred thinking and planning should result in the early identification of destination communities. With this knowledge, government and community efforts can focus on ensuring adequate preparation and resource allocation in those communities.
- Once the decision is made to close an institution, a comprehensive closure plan should be developed together with a strategy for communicating the decision and the process to the public.
- In anticipation of resistance from the community, governments and local/regional authorities must be well prepared with clear information about what is planned and why this decision is in everyone's best interest, especially the interests and rights of the citizens who are part of the process.
- Background information and fact sheets dealing with anticipated questions and concerns about institution closures should be developed and refined to address local issues.
- Media releases and strategies for promoting the plan and dealing with opposition should be crafted to ensure a focus on the rights of different groups of service users and respectful consideration of other interests.

### CASE STUDY 37: THE TAPS PROJECT

"... we mounted an experiment in south London around reprovion for Tooting Bec Hospital. We studied two staffed homes for discharged long-stay patients situated in adjacent districts. In one of the streets we ran an education campaign for the neighbours and surveyed their attitudes before and after the intervention. In the other street we conducted the two surveys at the same time interval, but without any educational input. Comparison of the experimental with the control street showed that the campaign was successful in increasing neighbours' understanding and reducing their fear of people with mental illness. These changes in attitude were reflected in behaviour, since some of the neighbours in the experimental street visited the patients and invited them to their homes, whereas there was no social activity of this kind in the control street. Moreover, the social networks of the experimental patients enlarged while those of the control patients remained static. We conclude that localised education campaigns are effective in improving the social integration of patients into their neighbourhoods."<sup>344</sup>

<sup>343</sup> Extract from People First of Canada/Canadian Association for Community Living, *op. cit.*

<sup>344</sup> See the TAPS Project, A report on 13 years of Research 1985–1998, published in the Psychiatriest. Available at: <http://pb.rcpsych.org/content/24/5/165.full>. See also The Caravan of Truth: Face to Face Conversations from Mental Health Compass, Database of Policies and Good Practices, available at: [https://webgate.ec.europa.eu/sanco\\_mental\\_health/public/GOOD\\_PRACTICE/1206/show.html](https://webgate.ec.europa.eu/sanco_mental_health/public/GOOD_PRACTICE/1206/show.html)





## Further reading

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## CHAPTER 9: DEFINING, MONITORING AND EVALUATING THE QUALITY OF SERVICES

*During the transition from institutional care to community-based services, and once community-based services are in place, it is crucial that institutional practices are not replicated in the community. This chapter sets out criteria that can be used to measure the quality of services. It highlights the need for ongoing monitoring and evaluation of services, and presents ways in which users of services can be involved in service evaluation.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

Under Article 33 of the CRPD, State Parties must establish a monitoring mechanism at the national level to oversee the implementation of the CRPD. Monitoring should consist of one or more focal points within the Government to deal with matters related to the implementation, as well as a coordinating body to facilitate implementation. States must also establish or strengthen an independent monitoring body, such as a national human rights body, to promote, protect and monitor the CRPD.<sup>345</sup>

### Obligations under the UN Convention on the Rights of the Child

Article 3 of the CRC states that services involved in the care or protection of children must conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

## 1. The importance of defining quality standards

In a system that relies on institutional care, standards tend to focus on the technical aspects of service provision, rather than on how services affect the quality of life of those using them. They cover mainly structural quality standards such as construction and interiors, health protection and hygiene, clothing and food, personnel and their wages, other resources and book-keeping. According to a UNICEF report<sup>346</sup>, such standards support the functioning of institutions as a mixture of hospital and army barracks. They also exclude any monitoring or evaluation of results.

Other problems in many countries that rely on institutional care include rigid and over-bureaucratic standards that support, rather than challenge the current system; little or no involvement of users, families or civil society in the development of quality standards; weak or non-existent implementation systems; under-developed or non-existent systems to regulate services and professions and under-developed or non-existent systems to monitor and evaluate practice.<sup>347</sup>

<sup>345</sup> United Nations, *op. cit.* (2007).

<sup>346</sup> UNICEF & World Bank (2003) *Changing Minds, Policies and Lives, Improving Protection of Children in Eastern Europe and Central Asia, Improving Standards of Child Protection Services*, p.7.

<sup>347</sup> *Ibid.*, p.8.



Developing standards needs to be seen in the framework of the overall deinstitutionalisation policy. It should go hand-in-hand with ending admissions to institutional care and redirecting resources into community-based services.<sup>348</sup>

The paradigm shift to individual support and person-centred planning requires a shift in how services are evaluated and how the standards are used.<sup>349</sup> The choice and definition of quality principles, standards or indicators is one of the key steps towards establishing an efficient regulatory system for services in the community.<sup>350</sup> Such standards must be linked to the rights and quality of life of service users, rather than focus on technical issues.<sup>351</sup> Especially during transition, accountability and being able to maintain a level of quality service across the service spectrum are important. This includes both budget monitoring, and a system for evaluating any support and services provided.<sup>352</sup>

In defining quality standards, the use of personal outcomes determined by people that use the services has, in many countries, emerged as the preferred option. In addition, it is not enough for evaluation to simply track what service providers are doing. Effective evaluation systems have to include mechanisms for both assuring and improving the quality of service and outcomes for people using the services.<sup>353</sup>

Finally, standards should be based on any good practice already existing in the country, or internationally, in order to avoid duplicating work.

## KEY GUIDANCE 12: RISKS ASSOCIATED WITH SETTING STANDARDS

The risks associated with developing standards<sup>354</sup> include situations in which they are developed for services which are inherently unable to deliver good quality of life for people using them, such as institutional care settings. Standards should also not be too detailed or rigid, which would prevent them from responding to individual needs. There are situations in which community-based services have to comply with standards more suited to institutional care settings, such as rules on ordering supplies, outside visitors and health and safety regulations.

Standards can at times be too abstract; quality frameworks can be turned into checklist exercises. There is also a danger in defining minimum standards, since it may lead to a situation when only those minimum standards are funded and service providers have no incentive to provide a service which goes beyond that.

In many countries, standards have a tendency to focus on the physical and tangible, such as size of space, amount and quality of food provided. However, it is equally important to have measurable standards regarding quality of care and quality of life.

Standards are ineffective unless they form part of a system of inspection that has adequate powers and resources to intervene where they are not being met.

348 *Ibid.*, p.9.

349 Power, *op. cit.*, p.37.

350 Chiriacescu, Diana (2008) Shifting the Paradigm in Social Service Provision, Making Quality Services Accessible for People with Disabilities in South East Europe, Sarajevo: the Disability Monitor Initiative, p.36.

351 UNICEF & World Bank, *op. cit.*, p.7.

352 Power, *op. cit.*, p.36.

353 *Ibid.*, p.37.

354 UNICEF & World Bank, *op. cit.*, p.8.



## CASE STUDY 38: COMPLYING WITH STANDARDS FOR INSTITUTIONAL CARE

In Austria, to create a small unit for older people with dementia, service providers have to comply with standards defined for institutional care. These standards (and other regulations such as on staffing) come into play as soon as there are five people in one setting. This is often used as an argument why a care home cannot be run economically with less than 70 residents.<sup>355</sup>

## 2. Implementing standards at different levels

The system of setting and monitoring quality standards engages different levels<sup>356</sup> – central government, local or regional government, service providers and third parties (such as certification agencies), as well as people using the services or their representative organisations.

UNICEF and the World Bank have proposed a number of actions that should be taken when moving from institutional care to support services in the community (Table 7). Even though they were proposed in relation to children's services, they can be applied to other user groups. They provide a useful overview of changes required in transition to community-based services and give an idea of the complexity of the process.<sup>357</sup>

**Table 7: Implementing standards at different levels**

Central government level	
Tasked with setting the strategic direction for services and establishing systems to develop and monitor quality services within an overall deinstitutionalisation policy.	<ol style="list-style-type: none"><li>1. Assess the current situation by reviewing current standards, regulations and monitoring mechanisms and identify exemplary practice.</li><li>2. Decide on type of standards, regulation mechanism and monitoring systems to be implemented.</li><li>3. Develop an implementation plan covering use of pilots, training and orientation of personnel and develop incentives to implement standards.</li><li>4. Create a legislative framework for standards and monitoring.</li><li>5. Set up regulatory bodies such as Inspectorates, Accreditation Councils, Professional Councils, Professional Training Councils, Ombudsmen, as required.</li><li>6. Develop data systems to collect information on the quality of services.</li><li>7. Develop and update standards, codes of practice (ethics), practice guidance, performance indicators and regulation through broad consultation gaining commitment and ownership and involving users and carers.</li></ol>

<sup>355</sup> Example obtained from the European Social Network.

<sup>356</sup> UNICEF & World Bank, *op. cit.*, p.8.

<sup>357</sup> *Ibid.*, pp.8–9.



### Local/regional level

Tasked with providing for, coordinating and planning the provision of services that are responsive to local needs.

1. Implementing or improving quality assurance mechanisms for service planning, management and purchasing of services, coordination of local services and directly-provided services.
2. Implementing or improving inspection services. If required set up inspection unit and recruit and train inspectors.
3. Implementing or improving systems to identify problems or opportunities for improving quality including information systems, complaints systems, problem reporting and identification mechanisms, surveys, statistical monitoring, research and performance measurement using indicators, benchmarking and quality teams.
4. Promoting understanding and acceptance of standards and performance improvement mechanisms by personnel, local communities, users and parents.

### Practice settings

To include a review of the organisation's services.

1. Assessing the current situation, identifying areas of exemplary practice and poor practice requiring change.
2. Selecting a quality improvement approach. This may focus on monitoring desired or adverse outcomes, or on service delivery and support processes to determine areas for improvement.
3. Setting up a team responsible for initial quality assurance activities.
4. If the service's mission is unclear, or if it is unresponsive to community needs, strategic planning might be required. To do this: define the organisation's mission; assess the opportunities and constraints in the external environment and the organisation's internal strengths and weaknesses and determine priorities.
5. Setting standards, developing guidelines, standard operating procedures and performance standards through a consultative process involving all personnel, carers and users.
6. Developing or improving monitoring systems such as information systems; complaints systems and indicators.
7. Developing a quality assurance plan covering the objectives and scope, responsibilities, and implementation strategies.
8. Reviewing achievements and restarting the process to implement ongoing improvements.





## 3. Defining the content of quality standards

### 3.1 European quality frameworks

At the EU level, social services are defined in the European Commission Communication on social services of general interest of April 2006.<sup>358</sup> They include services such as social assistance, long-term care, childcare, employment and training services, personal assistants and social housing. The objectives and principles which should guide the organisation of social services are set out in the 2007 Commission Communication on services of general interest and on social services of general interest. Among these is that social services must be “comprehensive and personalised, conceived and delivered in an integrated manner.”

#### 3.1.1 Voluntary European Quality Framework for Social Services

The European Quality Framework for Social Services (‘the Framework’)<sup>359</sup> was adopted in 2010 by the Social Protection Committee, with the aim of developing a common understanding of the quality of social services within the EU. The Framework identifies quality principles and proposes a set of methodological guidelines. These can be used by public authorities in the Member States to develop their own tools for the definition, measurement and evaluation of the quality of social services. The implementation of the Framework is voluntary and can be applied in the national, regional and local context.<sup>360</sup>

The European Quality Framework (summarised in the chart below) establishes the overarching quality principles for service provision. It covers three dimensions of service provision:

1. the relationships between service providers and users;
2. the relationships between service providers, public authorities and other stakeholders; and
3. human and physical capital.

For each of these, operational criteria (i.e. indicators) are listed, which should help countries to monitor and evaluate social services. For example, one of the quality principles is “respect for users’ rights”. The quality criteria include: providing workers and volunteers involved in service delivery with adequate training in rights-based, person-centred service provision of everyday care; and promoting users’ inclusion in the community.

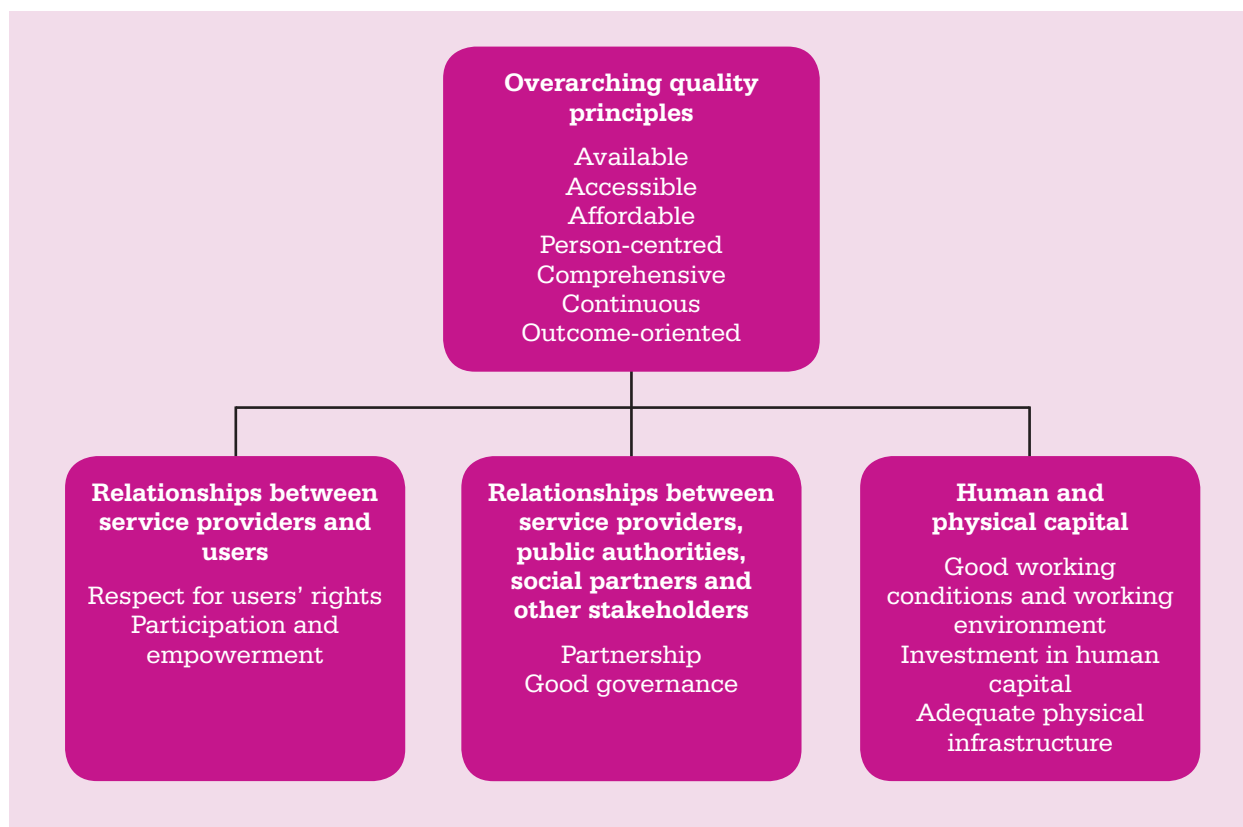
<sup>358</sup> Communication from the European Commission “*Implementing the Community Lisbon Programme: Social Services of General Interest in the European Union*” COM(2006)177 final.

<sup>359</sup> Social Protection Committee, *op. cit.*

<sup>360</sup> For further information, please see: <http://cms.horus.be/files/99931/Newsletter/FINAL%20-%20SPC-VQF-SSGI-10.08.10.pdf>



**Chart: Summary of the European Quality Framework for social services**



### 3.1.2 Other initiatives to define quality principles

At the European level, there have been a number of initiatives aiming to establish common quality principles for social and health services. The Social Platform has identified nine principles, each of which is followed by a set of indicators. For the Social Platform, a quality social and health service should:

1. respect human dignity and fundamental rights;
2. achieve expected results;
3. be tailored to each individual;
4. ensure the security of all users, including the most vulnerable;
5. be participative and empower users to make decisions on their own;
6. be holistic and continuous;
7. be provided in partnership with communities and other stakeholders;
8. be provided by skilled professionals working under good employment and working conditions; and
9. be managed in a transparent way and be accountable.

The European Platform for Rehabilitation has developed a set of European Principles of Excellence in Social Services (EQUASS) and offers three levels of accreditation. These are intended to complement certification programmes at the national level.<sup>361</sup> Accreditation is based on the ten EQUASS criteria: leadership, personnel/professionals, rights, ethics, partnership, participation, person centred, comprehensiveness, result orientation and continuous improvement – with more than 100 indicators

<sup>361</sup> For further information, see <http://www.epr.eu/index.php/equass>

used for the assessment. Some countries, such as Norway, have officially recognised the EQUASS certification system and use it for the allocation of public funding for rehabilitation services.

The Quality4Children Standards for Out-of-Home Child Care in Europe, developed by FICE International, SOS Children's Villages and IFCO, aim to inform, guide and influence those involved in out-of-home childcare. These include children and young people, biological families, care-givers, care organisation managers, social workers, representatives of public authorities and others. The Standards were developed in consultation with children and young adults who have experienced out-of-home care.<sup>362</sup>

As part of a European project against elder abuse, a group of organisations developed standards for services for the older people, based on the European Charter of rights and responsibilities for older people in need of long-term care and assistance. The guide<sup>363</sup> is accompanied by examples of good practice.

### 3.2 Schalock's Quality of Life Framework

When defining, monitoring and evaluating the quality of services, one needs to focus on how they affect the quality of life of people using them. Quality of Life, as defined by Prof. Robert Schalock, is a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they can vary individually in relative value and importance. The assessment of quality of life is therefore based on culturally sensitive indicators.<sup>364</sup> They are presented in Table 9.

Schalock's Quality of Life framework has a number of applications, including in policy development. For example, in the US, many laws involving people with intellectual disabilities require individual support plans that can be developed within the Quality of Life framework. The framework aligns support needs with quality of life factors and domains and includes the assessment of quality of life-related personal outcomes.<sup>365</sup>

Since the eight domains are in line with the UN Convention on the Rights of Persons with Disabilities, the framework can be used a tool for measuring the implementation of the Convention. It can also be used for reporting, monitoring, evaluation and continuous quality improvement to underpin the transformation of institutional care providers into community-based service providers.<sup>366</sup>

362 SOS-Kinderdorf International (2007) *Quality4Children Standards for out-of-home child care in Europe – an initiative by FICE, IFCO and SOS Children's Villages*. SOS-Kinderdorf International, Innsbruck, Austria.

363 European Charter of the Rights and Responsibilities of Older People in Need of Long-term Care and Assistance. Accompanying guide (2010). For good practice examples, see: <http://www.age-platform.eu/en/age-policy-work/quality-care-standards-and-elder-abuse/1077-good-practices>

364 Interview with Prof. Schalock by Expertise Centre Independent Living, published in the Newsletter of the European Network on Independent Living on 31 May 2011, available at: <http://www.enil.eu/news/interview-professor-robert-schalock/>

365 Wang, M., Schalock, R.L., Verdugo, M.A. & Jenaro, C. (2010). *Examining the factor structure and hierarchical nature of the quality of life construct*. American Journal on Intellectual and Developmental Disabilities, 115, 218–233, p.230.

366 Interview with Prof. Schalock, *op. cit.*



**Table 9: Schalock's Quality of Life Framework<sup>367</sup>**

Domain	Indicators and descriptors
Emotional Well-Being	<ol style="list-style-type: none"> <li>1. Contentment (satisfaction, moods, enjoyment)</li> <li>2. Self-concept (identity, self-worth, self-esteem)</li> <li>3. Lack of stress (predictability and control)</li> </ol>
Interpersonal Relations	<ol style="list-style-type: none"> <li>4. Interactions (social networks, social contacts)</li> <li>5. Relationships (family, friends, peers)</li> <li>6. Supports (emotional, physical, financial)</li> </ol>
Material Well-Being	<ol style="list-style-type: none"> <li>7. Financial status (income, benefits)</li> <li>8. Employment (work status, work environment)</li> <li>9. Housing (type of residence, ownership)</li> </ol>
Personal Development	<ol style="list-style-type: none"> <li>10. Education (achievements, education status)</li> <li>11. Personal competence (cognitive, social, practical)</li> <li>12. Performance (success, achievement, productivity)</li> </ol>
Domain	Indicators and descriptors
Self-Determination	<ol style="list-style-type: none"> <li>13. Autonomy/personal control (independence)</li> <li>14. Goals and personal values (desires, expectations)</li> <li>15. Choices (opportunities, options, preferences)</li> </ol>
Physical Well-Being	<ol style="list-style-type: none"> <li>16. Health (functioning, symptoms, fitness, nutrition)</li> <li>17. Activities of daily living (self-care, mobility)</li> <li>18. Health care</li> <li>19. Leisure (recreation, hobbies)</li> </ol>
Rights	<ol style="list-style-type: none"> <li>20. Human (respect, dignity, equality)</li> </ol>
Social Inclusion	<ol style="list-style-type: none"> <li>21. Legal (citizenship, access, due process)</li> <li>22. Community integration and participation</li> <li>23. Community roles (contributor, volunteer)</li> <li>24. Social supports (support networks, services)</li> </ol>

## 4. Monitoring and evaluation

### KEY GUIDANCE 13: MONITORING MECHANISMS AND UN GUIDELINES FOR THE ALTERNATIVE CARE OF CHILDREN

According to the UN Guidelines for the Alternative Care of Children, “Agencies, facilities and professionals involved in care provision should be accountable to a specific public authority, which should ensure, amongst other things frequent inspection comprising both scheduled and unannounced visits, involving discussion with and observation of the staff and children”. The Guidelines also set out the functions of the monitoring mechanism, which should, among others “recommend relevant policies to appropriate authorities with the aim of improving the treatment of children deprived of parental care”.<sup>368</sup>

<sup>367</sup> Wang, M., Schalock, R.L., Verdugo, M.A. & Jenaro, C. (2010). *Examining the factor structure and hierarchical nature of the quality of life construct*. American Journal on Intellectual and Developmental Disabilities, 115, 218–233, p.221.

<sup>368</sup> United Nations Guidelines for the Alternative Care of Children, para. 128–130.

Monitoring and evaluation are indispensable components of the planning and implementation of services. They can ensure transparency, accountability and control of all phases of service provision. Policies and strategies for monitoring and evaluation should be built into all stages of deinstitutionalisation, including the implementation of strategies, action plans for closure and individual plans.

Monitoring and evaluation should be performed in close cooperation with the actual and potential users of services and their families, as well as their representative organisations. Through the use of benchmarking procedures, evaluation can contribute to the promotion of innovative services and best practice. Most importantly, monitoring and evaluation can ensure compliance with quality standards: in other words, respecting the interests of the users and their active involvement in service provision.<sup>369</sup>

## 4.1 Monitoring

Effective monitoring requires setting up a range of mechanisms, which can include<sup>370</sup>:

- **Regulatory mechanisms** such as licensing, accreditation and certification.
- **Inspection:** using standards as the basis, inspections should result in a report highlighting good practice, areas for improvement and recommendations. In line with best practice, reports should be public.
- **Performance measurement and indicators:** increasingly used to assess the performance of services funded by the state; requires the existence of measurable indicators, which can give an accurate indication of the quality of the service.
- **Complaints system:** should provide protection for those making the complaints and an independent system for processing complaints.
- **Ombudsmen, children's (and other) advocates:** these can deal generally with the rights of different groups (and inform policy), as well intervene in individual cases.

In terms of what is monitored, the focus should be on the personal outcomes and satisfaction of each individual, i.e. the extent to which the wishes, preferences and needs of each individual (and their family, where relevant) are being addressed.<sup>371</sup> For children leaving institutional care, monitoring requires a recognition of indicators of placement breakdown, since these will require an urgent and appropriate response.<sup>372</sup>

## 4.2 Evaluation

Evaluation of services can be external and internal (self-evaluation). Before beginning evaluations, terms of reference should be drafted. These should outline:

- the objectives and scope of the evaluation;
- the methodology;
- the necessary resources and timetable; and
- how results will be communicated.

369 Chiriacescu, Diana, *op. cit.*, p.42.

370 UNICEF & World Bank, *op. cit.*

371 People First of Canada/Canadian Association for Community Living *op. cit.*

372 Mulheir, G. & Browne, K. *op. cit.*, p.133.



Those carrying out the evaluation should be adequately qualified or trained. Evaluations should target the structure, the process and the results of a particular service. They should be followed by recommendations for improvement. Results of the evaluation should also have implications for the continuation of the service and funding.

In evaluating services, the use of benchmarking is recommended. This refers to evaluation of the results achieved by a service provider in comparison with more successful or effective organisations, considered to be best practice.<sup>373</sup> Benchmarking can help services avoid repeating the same mistakes and promotes replication of best practice.

It is also important to monitor and evaluate the process of deinstitutionalisation itself. It is suggested that monthly reports should be prepared based on key indicators. They should include details of the individuals affected by the process, the personnel, development of new services and the financial position. A more detailed report can be prepared every six months, based on monthly reports. This could include qualitative information showing the service users' (and other stakeholders') satisfaction with the process. The final report can look into wider issues, such as analysis of the impact of the deinstitutionalisation programme on service users, families, personnel, local agencies and communities, along with lessons learned.<sup>374</sup>

### 4.3 Involving users in evaluating services

In the spirit of partnership, people using the services and their representative organisations, as well as families where relevant, should not only be involved in defining the quality standards, but also in the process of monitoring and evaluating services.

Quality evaluation from the client's perspective is about their personal experience with their housing, living, working conditions. The focus should be on the achievement of outcomes derived from the person's preferences and lifestyle. Different aspects can be evaluated:

- their satisfaction with certain aspects of their life and the support they are getting;
- the value and relative importance people attach to these aspects;
- the degree to which their individual needs, wants and preferences are met;
- the degree to which they can aim for personal objectives; and
- the degree to which they have the feeling that change or improvement is possible.<sup>375</sup>

While the principles of user involvement will be the same for all the groups, the way their involvement can be facilitated will be different. Organisations representing children, people with disabilities, people with mental health problems and older people should be consulted, so that the process gives a real voice to the people involved and empowers them to contribute to improving services.

373 Chiriacescu, Diana, *op. cit.*, p.42.

374 Mulheir, G. & Browne, K. *op. cit.*, p.135.

375 Inclusion Europe (2003) *Achieving Quality, Consumer involvement in quality evaluation of services*. Report. Brussels: Inclusion Europe, p.3.





### CASE STUDY 39: THE NUEVA EVALUATION MODEL, AUSTRIA<sup>376</sup>

The Nueva evaluation model was developed by the Atempo Association in Austria. Quality criteria, developed by people with intellectual disabilities, are formulated as questions for interviews with the users of services. There are different questionnaires for different kinds of services – some are for residential services and others for supported living services. For people who are not able to answer questions, observation criteria are used. There are between 60 and 120 criteria for different kinds of services, which are outlined in five to six quality dimensions. These quality dimensions were also defined by the users' group and should help users understand the results of the evaluation easily. When evaluating living services the dimensions are self-determination, security, private sphere, support, care and satisfaction. When evaluating workplaces, the quality dimensions are self-determination, normalisation and integration, security, support and satisfaction.

The Nueva evaluators and their assistants regularly organise quality circles with users, staff and representatives of authorities in order to discuss with them which quality criteria they want to add or to remove. As a result of these quality circles and various research projects, the definitions for quality are reconsidered every two years for improvement.

The methods used to collect information are both quantitative and qualitative. Nueva evaluators conduct structured interviews (verbally and with picture support), undergo structured observations and participative observations, as well as analyse written questionnaires to evaluate the structural and processes data. Within the qualitative approach, they carry out workshops with users and staff members in order to discuss with them their target states and ideas for quality improvement.

After data collection the Nueva evaluators enter the data in a database for statistical analysis. This was specially developed in an accessible format for people with disabilities. Nueva evaluators are trained for two years in order to become experts in quality of services for their peer group and to be able to conduct interviews of people with disabilities.

In the Nueva model, the evaluators are people with intellectual disabilities. They do not only define quality in their own perspective but also undertake the interviews. The evaluated services are presented in an online catalogue, where people can search through the database according to different criteria.

## 5. Inspecting and evaluating institutional care

The process of developing alternatives to institutional care may take a long time, especially in countries where the number of people in institutions is very high. Therefore, during this process, it is important to ensure that the rights of those who remain in institutional care are respected.

A European report<sup>377</sup> recommends that countries establish independent inspectorates which will have guaranteed access to all institutions and be able to make unannounced visits. They recommend the publication of comprehensive reports and cooperation with civil society, in particular organisations which represent users of such services. The legally mandated inspectorates should also be able to deal with any individual complaints.

<sup>376</sup> Atempo & Inclusion Europe (2010), *User Evaluation in Europe, Analysis of Existing User-evaluation Systems at National Level*, available at: [www.nueva-network.eu/cms/index.app/Index/download/?id=139](http://www.nueva-network.eu/cms/index.app/Index/download/?id=139)

<sup>377</sup> MDAC (2006) *Inspect!.* Inspectorates of Mental Health and Social Care Institutions in the European Union. Budapest: Mental Disability Advocacy Centre.





Another aspect that should not be neglected is the quality of care in institutions during the process of transition and closure. Every effort should be made to improve the quality of care, especially where the residents' health and safety is at risk. Maintaining quality is particularly challenging where personnel are being made redundant. Involving personnel in every stage of the reform and assisting them to learn new skills while the institution is closing (such as assessing children and preparing them for the transition) has proven to assist in maintaining the quality of care.<sup>378</sup>

#### CASE STUDY 40: EXAMPLES OF TOOLS FOR EVALUATING QUALITY OF CARE IN RESIDENTIAL SETTINGS

**WHO Quality Rights Tool Kit** provides countries with practical information and tools for assessing and improving quality and human rights standards in mental health and social care facilities. The Toolkit is based on the United Nations Convention on the Rights of Persons with Disabilities.<sup>379</sup>

**The E-Qalin** is a quality management system for care homes, home care facilities and services for people with disabilities. It is based on training of E-Qalin process managers and a self-assessment process in the organisation during which 66 criteria in the area of 'structures & processes', and 25 foci in the area of 'results' are assessed. By involving all stakeholders in the self-assessment and the continuous improvement of quality, E-Qalin strives to strengthen the individual responsibility of staff and their ability to cooperate across professional and hierarchical boundaries.<sup>380</sup>

**www.Heimverzeichnis.de** is an initiative which has grown out of consumer protection. It aims for more transparency and better information for users of residential care services in Germany. In addition to publishing structural data concerning the number of places, the infrastructure and prices, the website highlights those care homes in which high standards for the quality of life of their residents are achieved. The criteria, against which quality of life is measured and assessed in the participating organisations, were developed by associations of care homes, representatives of health insurance funds, interest groups of seniors and institutions for consumer protection.<sup>381</sup>

### Further reading

Atempo & Inclusion Europe (2010) *User-Evaluation in Europe: Analysis of Existing User-Evaluation Systems at National Level*, UNIQ – Users Network to Improve Quality.

Center for Outcome Analysis (USA) – <http://www.eoutcome.org/>

Chiriacescu, D. (2008) *Shifting the Paradigm in Service Provision: Making Quality Services Accessible for People with Disabilities in South East Europe*, Disability Monitor Initiative, Handicap International.

378 Mulheir, G. & Browne, K. *op. cit.*, p.106.

379 For further information see: [http://www.who.int/mental\\_health/publications/QualityRights\\_toolkit/en/index.html](http://www.who.int/mental_health/publications/QualityRights_toolkit/en/index.html)

380 For more information see: <http://interlinks.euro.centre.org/model/example/e-qalin>

381 For more information see: [http://interlinks.euro.centre.org/model/example/wwwHeimverzeichnisde\\_CertifiedQualityOfLifeInNursingHomes](http://interlinks.euro.centre.org/model/example/wwwHeimverzeichnisde_CertifiedQualityOfLifeInNursingHomes)





Inclusion Europe (2003) *Achieving Quality, Consumer involvement in quality evaluation of services*. Report. Brussels: Inclusion Europe.

MDAC (2006) *Inspect!*, Inspectorates of Mental Health and Social Care Institutions in the European Union. Budapest: Mental Disability Advocacy Centre.

Schalock, R. et al. (2007) *Quality of Life for People with Intellectual and Other Developmental Disabilities: Application across individuals, organizations, communities, and systems*. Washington, DC: AAIDD.

UNICEF & World Bank (2003) *Changing Minds, Policies and Lives, Improving Protection of Children in Eastern Europe and Central Asia, Improving Standards of Child Protection Services*.

## Tools

UNICEF & World Bank (2003) *Toolkit for Improving Standards of Child Protection Services in ECA Countries*.

SOS-Kinderdorf International (2007) *Quality4Children Standards for out-of-home child care in Europe – an initiative by FICE, IFCO and SOS Children's Villages*. SOS-Kinderdorf International, Innsbruck, Austria, available at: [http://www.quality4children.info/content/cms,id,89,nodeid,31,\\_language,en.html](http://www.quality4children.info/content/cms,id,89,nodeid,31,_language,en.html)

WHO Quality Rights Tool Kit (2012) Available at: [http://whqlibdoc.who.int/publications/2012/9789241548410\\_eng.pdf](http://whqlibdoc.who.int/publications/2012/9789241548410_eng.pdf)





## CHAPTER 10: DEVELOPING THE WORKFORCE

*There is a strong link between personnel and the successful development and maintenance of quality services in the community. The availability of trained personnel to work in the community will affect how quickly new services can be put in place. Most importantly, well-trained and motivated personnel can ensure that institutional practices are not replicated in community settings.*

*This chapter outlines a process of workforce development that countries can follow while moving from institutional to community-based services in order to sustain the provision of quality services in the community.*

### Obligations under the UN Convention on the Rights of Persons with Disabilities

In line with Article 4(1)(i) of the CRPD, State Parties should “promote the training of professionals and staff working with persons with disabilities in the rights recognised in the present Convention so as to better provide the assistance and services guaranteed by those rights”. They must also ensure that there is initial and continuing training for professionals and staff working in habilitation and rehabilitation services (Article 26).

In line with the general obligations of the CRPD, in developing and carrying out training for the professionals and staff, countries should “closely consult with and actively involve” persons with disabilities, including children with disabilities, through their representative organisations (Article 4(3)).

### Obligations under the UN Convention on the Rights of the Child

Article 3 of the Convention obliges State Parties to ensure that there is an adequate number of suitable staff involved in care or protection of children.

## 1. Planning stage

### 1.1 Paradigm shift

The paradigm shift (medical model to social model, patient to citizen, object of care to rights holder) involved in the transition to community-based services will strongly affect the staffing of services. The range of professions and roles required in the community will be different from those in the institutions. Whereas in institutional care, positions tend to be occupied by medical personnel such as doctors and nurses alongside administrative and maintenance personnel, this will not be the case for services in the community. In addition to social workers, teaching assistants in schools, speech therapists, occupational therapists, home-help personnel, new roles will need to be introduced. These might include personal assistants, carers and advocates. The role, rights and responsibilities of informal carers (including volunteers) should also be considered.



Moreover, if mainstream services are to become accessible to all, it is important to plan for the training needs of personnel in all the relevant sectors, including health, education, employment and transport, culture and recreation.

## 1.2 Workforce strategy

“The aim should be to take people and organisations from where they are and, by involving all relevant stakeholders, develop quality towards defined goals and objectives. This calls for quality management and respective training and guidance.”<sup>382</sup>

Identifying personnel requirements for the new services will be one of the first steps in the planning process. This is sometimes referred to as the workforce strategy, or human resource plan. The strategy will deal with the staffing requirements for community-based services, skills development and professional development requirements, in addition to the human resource management aspects of the transition.<sup>383</sup> It should go hand-in-hand with the assessment of the situation (see Chapter 2), as staffing needs will very much depend on what is already available (including the skill set of existing personnel) and the range of services that will be developed in the community.

It is important that the strategy encompasses both management and support personnel and that there is good coordination between national and local strategies. The national level strategy should support those at lower levels. Models of good practice developed in existing community-based services can be used in this process.<sup>384</sup>

In addition to the paradigm shift and the changing role of personnel, it is likely that the following factors will influence the process<sup>385</sup>:

- Diversified services, requiring an increased number of professionals.
- The need to support people with different needs in mainstream services.
- Reduction in the number of administrative posts required.
- Change in the geographical location of services, with services following the users (as opposed to institutional care).

Once the profile and number of personnel needed in the new services, as well as their location, is available, comparison should be made between the currently available posts in the institutional services and the requirements of services in the community. The comparison will make it easier to anticipate where dissatisfaction and resistance may arise, which in turn will allow planning of an appropriate strategy to address these issues.

<sup>382</sup> Quote obtained from the European Social Network during the consultation on the Guidelines.

<sup>383</sup> Health Service Executive, *op. cit.*, p.110.

<sup>384</sup> *Ibid.*, p.110.

<sup>385</sup> Mulheir, G. & Browne, K. *op. cit.*, p.116.





## 2. Selection of personnel

It is important that the personnel are selected and trained (or re-trained) just before the new services open. It is recommended that the selection process is a competitive one based on application and interview. As a matter of good practice, service users from the community should form part of the selection committees.

For applicants who have worked in the old service (such as an institution that is closing down), an appraisal of their work in the old service should be considered as part of their application. For personnel who have spent a long time working in institutional care, and who may have become 'institutionalised' themselves, their potential to change should be taken into account.<sup>386</sup> Particular attention should be paid to ensure that individuals who are likely to engage in abusive behaviour towards the users in the new service (as they may have done in the institution) are screened out during the selection process.

Some methods for evaluating the potential of personnel from the old services to work in the new services can be found in *De-institutionalisation of Children's Services in Romania*.<sup>387</sup>

## 3. Training and re-training

### CASE STUDY 41: TRAINING DELIVERED BY PEOPLE WITH DISABILITIES

In one innovative approach to education and training, people with disabilities educate students and health care providers on a wide range of disability issues, including discriminatory attitudes and practices, communication skills, physical accessibility, the need for preventive care and the consequences of poor care coordination. Training delivered by people with physical, sensory, and mental health impairments may improve knowledge of issues experienced by people with disabilities.<sup>388</sup>

A systematic and coordinated training curriculum is a precondition for the establishment of services in the community and in ensuring personnel will be adequately trained. Training curricula need to take into consideration initial education, in-service training and life-long learning.<sup>389</sup>

The starting point for a training curriculum should be the desired competencies of the workforce. It is recommended that a core training curriculum is developed for each service and role-specific components can then be added to this. For example, a core curriculum for personnel working with children with intellectual disabilities would include an understanding of what 'intellectual disability' (ID) is and strategies for communicating with children with ID. It would also cover the skills and tools needed to support a child's educational and vocational transition to adulthood.<sup>390</sup>

386 *Ibid.*, p.118.

387 See Appendices in Mulheir, G. & Browne, K. *op. cit.*

388 World Health Organisation & World Bank, *op. cit.*, p.79.

389 World Health Organisation (2010b) *Build workforce capacity and commitment* (Better health, better lives: children and young people with intellectual disabilities and their families. Bucharest, Romania, 26–27 November 2010), p.5.

390 *Ibid.*, p.6.





Foster carers also require initial and ongoing professional training and support. The training should involve experienced foster carers as trainers, as well as young people currently living in care and those that have graduated from the care system. It is also important to recognise the role and the needs of birth children of foster carers and to provide appropriate training and support.

Central to any curriculum or training programme should be the rights of children, people with disabilities, people with mental health problems and older people. A WHO background paper on building workforce capacity and commitment highlights that this requires more than just a tokenistic mention of rights -: “it requires measurable outcomes and demonstrable rights in practice rather than rights in principle”.<sup>391</sup> Involvement of user groups (and their families, where relevant) in the design and delivery of training can help achieve this objective. There is a risk in giving academics and social or health care professionals the sole responsibility for training curricula.

Human rights standards and guidelines, such as the UN Guidelines for the Alternative Care of Children, should form part of the relevant curricula, in addition to materials developed by organisations representing users of services and service providers.

#### **CASE STUDY 42: EXAMPLE OF AN IN-SERVICE TRAINING PROGRAMME IN THE MENTAL HEALTH NURSING SECTOR<sup>392</sup>**

The in-service training programme should be based on the following principles:

**Less experienced personnel have very different training and support needs;** therefore the training should help them:

- develop a strong emotional link with people with disabilities;
- translate their knowledge into practice; and
- understand the needs and the difficulties of people with disabilities who have experienced years of institutionalisation.

**More experienced personnel** require support and supervision on more complex issues:

- avoiding burn-out phenomena;
- creating a long-standing emotional bond with people with disabilities and processing important or unexpected events during the rehabilitation route;
- adapting to a group method of work that is based on the differences among the specialties within the group and the benefits they bring;
- good coordination with other partners in the team with the aim of cultivating a supportive environment and enhancing morale; and
- the need to keep updated on current methodologies, approaches and practices.

<sup>391</sup> *Ibid.*, p.3.

<sup>392</sup> Jones, J., & Lowe, T. (2003) *The education and training needs of qualified mental health nurses working in acute adult mental health services*. Nurse Education Today, 23(8):610–9.





## 4. Professional values and ethics of the social work professionals

*“Social workers should respect and promote people’s right to make their own choices and decisions, irrespective of their values and life choices ...”<sup>393</sup>*

Social work is one of the key professions required for a community-based model of care and support. Social workers are often the link between the person and the services and benefits to which they may be entitled. They have to use their professional judgment to balance advocacy on a person’s behalf with the control of resources and respect for the law and due process. Social work is based on respect for the inherent worth and dignity of all people; from this follows an approach that empowers individuals with different support needs to live independent and fulfilling lives. The International Federation of Social Workers (IFSW) notes that “social work grew out of humanitarian and democratic ideals, and its values are based on respect for the equality, worth, and dignity of all people.”

Social work endorses a number of values that are very difficult to enact in an institution-based model of care, for example freedom of choice. If a person is living in an institution, typically the rigidity of routine does not allow them to make everyday choices, let alone life choices. Social inclusion and the central importance of human relationships are also among the values of professional social work. In the case of community-based care, this commitment could translate into nourishing contacts between people, their family and the wider community. This ambition cannot be realised when people are isolated in institutions that segregate them from the rest of society.

To enable this, the values and ethics of all social and health professions may need to be revisited, adapted or even completely rewritten to reflect the transition.<sup>394</sup> In the 21st century, the key values for social work should be read in favour of empowering, inclusive community-based services that promote users’ independence and participation by treating each person as a whole and identifying their strengths.

### Developing the social work workforce

A USAID report<sup>395</sup> looking at social work education and practice environment in Europe and Eurasia highlights the role of well-trained social work professionals in the creation of an effective system of social services. Building the social work profession involves creating legislation and education programmes, developing and strengthening curricula, supporting professional associations of social workers, developing licensing and practice standards and raising awareness about the need for social workers. The report presents a four-pillar framework for analysis and reporting, which has been used to highlight models of best practice in community-based practice. This framework can also be used to monitor and evaluate the state of social work in a given country. It is presented in Table 10.

The report highlights the link between social work practice and the quality of service delivery. The standards for social work practice, which should include an ethical code, clearly demonstrate what the practice and its desired outcomes should be. This can be combined with awareness-raising initiatives to improve the public image of social workers, all of which should contribute to increased interest in the profession and improved retention of qualified personnel.<sup>396</sup>

393 Taken from the Code of Ethics for Social Work by the International Federation of Social Work, available at: <http://ifsw.org/policies/statement-of-ethical-principles/>

394 Taken from the International Federation of Social Workers (IFSW), <http://ifsw.org/resources/definition-of-social-work/> and <http://ifsw.org/policies/code-of-ethics/>

395 Davis, R. *op. cit.*, p.ix.

396 *Ibid.*, p.xiv.



**Table 10: Four-pillar framework for analysis and reporting<sup>397</sup>**

<p><b>Pillar 1 – Policy and Legal Framework</b></p> <p>Policies and laws that reflect internationally recognised standards for the profession of social work, legal/policy mandates for social work practice that reflect good practice for community care models, and laws related to social work associations.</p>	<p><b>Pillar 2 – Structure of Services and Practice Environment</b></p> <p>Programs and services in which social workers practice, qualifications, relationships with other social workers, role of social work associations, job functions, salaries, status, relationships with clients, other professionals, and the public authorities.</p>
<p><b>Pillar 3 – Education and Training</b></p> <p>Acquisition of knowledge, values and skills for social workers providing direct services and those managing and supervising services. This includes professional education and training, curriculum development activities and conferences and workshops delivered by a range of providers.</p>	<p><b>Pillar 4 – Outcomes and Performance Measures</b></p> <p>Outcomes for social work interventions, systems for monitoring social work inputs, cost-benefits analyses, development of evidence-based practices, research on the professionalisation of social work such as salaries, standards, opinions and attitudes, client satisfaction, client outcomes and evaluations of programs and services.</p>

## 5. Barriers to developing the workforce

### 5.1 Resistance of personnel to closure of the institution

Resistance of institutional care personnel to closure is likely to be one of the major barriers in the transition to community-based services. However, good communication and the engagement of personnel at various stages of transition can help minimise this resistance and ensure that personnel performance does not deteriorate during the process of closure. Experience shows that even those facing redundancy are likely to be cooperative if this process is handled well.

### 5.2 Shortage of professional personnel

In some countries there is a severe shortage of qualified professionals to carry out services in the community. The introduction of professions such as personal assistants, occupational therapists, careers coaches, psychologists, foster parents and social workers does, in some countries, require not only training and certification but also legal recognition and budgeting at a national level.<sup>398</sup>

The regulatory framework for professional groups is insufficient in some countries. Moreover, there is a tendency for psychologists, pedagogues, sociologists and other professionals to occupy positions such as personal assistants, carers, occupational therapists, due to the lack of adequately qualified individuals for these roles.<sup>399</sup>

<sup>397</sup> Davis, R. *op. cit.*, p.x.

<sup>398</sup> Chiriacescu, Diana, *op. cit.*, p.145.

<sup>399</sup> *Ibid.*, p.144.



### 5.3 Migration

Because of the low status assigned to social work and other professions in certain countries (mainly in Central and Eastern Europe), there is a high level of migration of professional personnel to other European countries. When combined with the overall shortage of professional personnel to work in the new services, this can be a major barrier.<sup>400</sup> In many countries it requires an increase in social workers' salaries in order to reflect the professional value of work the role requires and to prevent regular turnover of personnel.

At the same time, those countries that receive the migrants face the issue of jobs in the care sector being occupied by largely untrained migrants who care mainly for older people with support needs (the so-called 'badanti' in Italy and '24-hour-assistance' in Austria). In many cases such individuals are working illegally so they are not subject to control or regulation.<sup>401</sup>

### 5.4 Problems of management politics, preferential treatment and corruption

In some countries, managers of services are appointed on the basis of their alliance with the ruling political party. Problems of preferential treatment, sometimes referred to as 'clientelism'<sup>402</sup>, can also exist in the leadership of non-governmental organisations, who may be linked to a particular party at a local (or other) level. This results in a lack of consistency and accountability in the management of services, with managers changing as a result of political elections. In the context of service reform, which is a long process, this presents a major barrier and can hamper or reverse progress towards community-based services. It is therefore recommended that managers of social, health and education services are appointed on the basis on their qualifications and demonstrated ability to lead and manage services. Special attention should also be paid to training and retaining senior and middle management personnel.<sup>403</sup>

It should be recognised that corruption can also be a major barrier to reform, with different economic interests tied to keeping institutions running. Any suspicion of corruption should be investigated and dealt with using appropriate channels.

### Further reading

Felce, D. (1994) *The quality of support for ordinary living: staff:resident interactions and resident activity*. In: *The Dissolution of Institutions: an International Perspective* (eds. J. Mansell & K. Ericsson), Chapman & Hall, London.

Mulheir, G. & Browne, K. (2007) *De-Institutionalising and Transforming Children's Services: A Guide to Good Practice*. Birmingham: University of Birmingham Press.

World Health Organisation (2010) *Build workforce capacity and commitment*. (Better health, better lives: children and young people with intellectual disabilities and their families. Bucharest, Romania, 26–27 November 2010)

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<sup>400</sup> *Ibid.*, p.144.

<sup>401</sup> Hitzemann, A., Schirilla, N. & Waldhausen, A. (2012), *Care and Migration in Europe. Transnational Perspectives from the Field*, Freiburg im Breisgau; and Di Santo, P. & Ceruzzi, F. (2010), *Migrant care workers in Italy: A case study*, Vienna: Interlinks, available at: [http://interlinks.euro.centre.org/sites/default/files/WP5\\_MigrantCarers\\_FINAL.pdf](http://interlinks.euro.centre.org/sites/default/files/WP5_MigrantCarers_FINAL.pdf)

<sup>402</sup> Where resources are (legally) exchanged for support in an asymmetric relationship.

<sup>403</sup> World Health Organisation *op. cit.* (2010b), p.9.





## Tools

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



# Frequently Asked Questions (FAQ)

## How big should a residential care setting be in order not to become an institution?

The smaller the setting, the more likely it is to provide a personalised service and facilitate social inclusion. However, even the smallest residential services can reproduce institutional culture. Some of the characteristics of institutional culture include:

- depersonalisation – removal of personal possessions, signs and symbols of individuality and humanity;
- rigidity of routine – fixed timetables for getting up and going to bed, eating and activities, irrespective of personal preferences or needs;
- block treatment – processing people in groups without privacy or individuality; and
- social distance – symbolising the different status of personnel and residents.

The focus should therefore be both on ensuring that the residential settings, if they exist at all, are small in size and that they do not reproduce institutional culture.

## Is it possible to provide high-quality care and support in an institution?

While it is possible to improve the quality of care and the material conditions, life in an institution can never match living in the community. Relationships with families and friends and participation in the life of the community cannot be achieved in institutional settings. Living in the community is not just about *where* one lives, but also about *how* one lives: developing relationships, going to school or work, going to the cinema or sports events and in generally enjoying a life similar to that of others. One of the key characteristics of institutions is that they segregate people from the community: this will not change regardless of the quality of care or the material conditions.

## Some people prefer to live in residential settings or in separate communities.

Everyone should be able to choose where and how to live and this choice should be respected. However, sometimes people may decide to move to a residential setting because there is no adequate support in the community or because the dominant view of them as less valuable puts pressure on them to withdraw for the society. They may not want to be a 'burden' to their families, or may face pressure from their families to move to residential care. Some decisions not to live in the community might be based on fear of the unknown (their own or their families'), because they have never had the opportunity to live anywhere but an institution. Therefore, every effort should be made to develop a range of options in the community and to ensure that all people are seen as valuable members of society.





### **There are children and adults who need care 24/7. Isn't residential care better for them?**

Continuing care can be provided in any setting – in a residential institution as well as in the home of the person. The person and their family should be able to choose where and what kind of support they receive. People rarely require 24/7 medical care, in which case they can live independently or with their families (in case of children) and access medical care as needed. The needs of informal carers should be considered and addressed together with the needs of the child or the adult for whom they care. Families can be trained to provide assistance with procedures that are usually carried out by a medical professional, such as tube-feeding or suction. This can be monitored by community nurses and special equipment can be provided in a person's home.

### **Independent living in the community is not suitable for people who are more vulnerable as there is a higher risk to their health and safety.**

There is no sound basis for the claim that living in the community comes with higher risks to health and safety of the person concerned. Frequent cases of abuse and poor quality care in residential settings around the world show that the assumption that residential care is a safer option is simply wrong. In both residential care and community living, safeguards should be in place to prevent risks (without being overly protective) and to ensure timely and adequate responses to ensure the safety of the individual.

### **Deinstitutionalisation of some people with mental health problems could pose a threat to their families and the wider community.**

Although it is quite common to think that people with mental health problems are a potential threat to the community, research shows that they are 2.5 times more likely to become victims of violence compared to other members of society. In fact, people with mental health problems need support, not seclusion. While there is prejudice about people with mental health problems or past psychiatric diagnoses being more prone to violence, the reality is that they are more often victims (rather than perpetrators) of discrimination, exclusion and violence. Therefore, when developing community-based services, we should not focus on protecting the community, but on implementing checks and balances to ensure that people with mental health problems cannot be exploited by others.

### **How long should the process of deinstitutionalisation take?**

The length of the process will depend on a number of factors, including the level of institutionalisation, the presence of a clear and shared vision, the existence of strong leaders, the strength of user-led organisations and the existence of sufficient, well-qualified professionals to manage the process of change. What is important is to look at deinstitutionalisation not only as an effort to close residential institutions. Such a narrow understanding may lead to a search for quick and easy solutions and eventually to a proliferation of small-scale residential services, such as group homes, instead of real community-based and family-based options. Deinstitutionalisation requires a complete transformation of the social care and child protection systems towards prevention and development of community-based services, as well as comprehensive changes in all other systems (such as health, education and housing), in order to ensure that all children and adults have access to high-quality mainstream services. Measures should therefore be implemented simultaneously in a number of policy areas in order to ensure the sustainability of reforms.







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To download the Guidelines in English and a number of other languages, please visit [www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu)





The Common European Guidelines on the Transition from Institutional to Community-based Care provide practical advice about how to make a sustained transition from institutional care to family-based and community-based alternatives for individuals currently living in institutions and those living in the community, often without adequate support. The Guidelines are aimed primarily at policy and decision makers in the European Union and the neighbouring countries with responsibility for the provision of care and support services for children, people with disabilities and their families, people with mental health problems and older people.

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