

# Developing Community Care

An ESN report that makes the case for community care, outlines the first steps in deinstitutionalisation and identifies key elements for good community care.

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Independence  
and dignity

Vision and  
leadership

A life like others  
and with others

ESN Policy &  
Practice Group  
ESN High-Level  
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Focus on the person not the structure

Community living for all

An informed choice for users

Social inclusion for everyone



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# ESN'S WORK ON 'DEVELOPING COMMUNITY CARE'

Developing Community Care has been an important strand of ESN's work programme funded by the European Commission since 2008. 'Managing Change: Role of Public Authorities in Deinstitutionalisation', ESN's training programme for local and regional authorities in the New Member States, was launched in 2011. ESN is also active at the European level in the European Expert Group on Transition from Institutional to Community Care.

This report was written by Dorota Tomalak (Policy & Development Officer) in collaboration with Stephen Barnett (Policy Director) and John Halloran (Chief Executive). The report draws on policy material, practice examples and advice from ESN's Policy & Practice Group on Developing Community Care (2009-2010) and its High-Level Advisory Committee on Developing Community Care; ESN thanks both groups for their close involvement from conception to comments on structure and language.

## ABOUT ESN

The European Social Network (ESN) brings together people who are key to the design and delivery of local public social services across Europe to learn from each other and contribute their experience and expertise to building effective social policy and practice. Together with our Members we are determined to provide quality public social services to all and especially to help improve the lives of the most vulnerable in our societies.

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The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies across the EU-27, EFTA and EU candidate and pre-candidate countries.

To that effect, PROGRESS 2007–2013 aims to:

- provide analysis and policy advice on employment, social solidarity and gender equality policy areas;
- monitor and report on the implementation of EU legislation and policies in employment, social solidarity and gender equality policy areas;
- promote policy transfer, learning and support among Member States on EU objectives and priorities;
- and relay the views of the stakeholders and society at large.

Find out more about PROGRESS: [www.ec.europa.eu/progress](http://www.ec.europa.eu/progress).



The information contained in this report does not necessarily reflect the position or opinion of the European Commission.

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More policy & practice resources produced by this group are available at: <http://www.esn-eu.org/towards-community-care>

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The European Social Network retains responsibility for any mistakes or inaccuracies contained in the text.

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# FOREWORD

Dear Readers,

European Social Network has been actively campaigning for deinstitutionalisation, i.e. the transition to community-based services, for several years. Besides establishing its own Policy & Practice Group and a High-Level Advisory Committee, ESN has also been a member of the *European Expert Group on Transition from Institutional to Community Care*, which has raised awareness of the issues at European level and advised on the use of European funds for deinstitutionalisation. Most recently ESN has launched a training programme for participants from the Czech Republic, Hungary, Poland and Slovakia.

ESN represents the municipalities, counties and regions which plan, design, fund and may also provide social services, whether in institutions or in the community. If the remaining institutions in Europe are to close and their (former) residents live independently in normal houses and flats on normal streets, local and regional authorities must play a leading role.

This report sets out to build a better understanding of what community care is really about and to raise awareness of its human, social, economic and political benefits.

Best regards,



John Halloran  
Chief Executive  
European Social Network

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# Developing Community Care

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*Executive  
Summary*

*Glossary*

*Introduction*



# EXECUTIVE SUMMARY

## Key Message

The transition from institutional to community-based care is desirable and – despite difficulties – achievable if we all play our part in this process. Researchers, European Union institutions and Member States can contribute to the success of this important change in the pattern of service provision. ESN is committed to a vision of Europe where everyone has the opportunity to live as normal a life as possible alongside others.

## Introduction

Most people take living in and being a part of the community for granted. And yet in Europe this is not the case for more than 1.2 million persons with disabilities, 300 000 persons with mental health problems and 150 000 children<sup>1</sup> who are estimated to be living in long-stay institutions. The persistence of the institutional model of care is one of the major challenges facing the European Social Model.

## Making the case for community care

There is a strong case for community over institutional care from the perspective of service users' experiences, human rights, social work values and value for money.

The [testimonies of former residents](#) confirm that whilst institutions may well provide physical security, food and shelter, they cannot offer the sense of well-being that

stems from being included in society, loved and valued by friends and relatives. As one former resident said, *“even a piece of bread tastes nicer at home.”*

International [human rights and principles](#) also clearly favour care in the community. Respect for inherent dignity, individual autonomy and the freedom to make one's own choices are well-recognised rights, which should not be denied to anyone on the basis of a disability, age or mental health status.

Social work is based on respect for the inherent worth and dignity of all people. Care in institutions too often takes people's dignity away, creates a strong hierarchy and forces residents to follow a set routine whether or not it suits them and their needs. It is clear that [social work principles](#) favour community-based services that promote users' independence and participation by relating to each person as an individual with their own particular needs, preferences and strengths.

The [economic case](#) has been hampered by the perception among policy-makers and service providers that only large institutions are capable of producing the economies of scale required for care to be affordable. The evidence suggests that community care is not necessarily more expensive than institutional care. In fact, it emerges as more cost-effective when one takes into service users' better quality of life.

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<sup>1</sup> ESSC, 6-8 July 2011 Warsaw, Presentation by Jan Pfeiffer, chair of the plenary session 'Towards Community Care' available at: <https://esn-conference.org/sites/default/files/Jan%20Pfeiffer.pdf>

## Making the first steps towards community care

The transition to community care can only be successful if based on a clear shared vision, which residents have helped to shape and which is driven forward by local political and professional leadership.

Creating a [vision for deinstitutionalisation](#) means making a mental picture of a community where people no longer live in institutions but receive care at home or in a home-like environment. Such a vision can be a powerful source of inspiration and should underpin operational decision-making required to successfully develop community care.

[Local leadership](#) is needed to bring about a change of focus on people rather than structures. This change will require additional funding to cover the transitional [costs](#) of maintaining the institution, whilst investing staff retraining and in new facilities as a hub for community-based interventions. The transition to community care entails detailed planning and careful management.

Deinstitutionalisation cannot be successful without [the involvement of users, their families, care staff and the community](#) in which they are to live. The European Ad-Hoc report contains a Basic Common Principle for the transition from institutional to community-based care:

*“Users (and their families) should be full partners in the transition process. They should be actively involved and consulted in the development, delivery and evaluation of the services.”*

Residents’ [relatives](#) play a key role in making or breaking deinstitutionalisation projects. The [staff](#) also need to be included from the early stages and have opportunities to (re)train to

work in community-based services. Success also relies on support from where former residents are likely to live. An open and accepting [community](#), made up of neighbours, business and civil society groups, can greatly enhance former residents’ independence and social inclusion.

## Making it work

There are a number of key elements that need to be in place in order to ensure an effective and coordinated delivery of community care.

[Strategic area needs assessment and planning](#) is a process that identifies the current and projected social and health needs of the local population, drawing on socio-economic data and qualitative input from local people. In institution-based models, strategic planning may not extend beyond issues of capacity and budget. In a community-based model, there can be a more fundamental assessment of whether the services are meeting citizens’ needs and preferences.

[Information and advice](#) are essential for everyone who may need care and support. At first sight, it may seem easier for an institution to publicise itself: there are constant elements, such as capacity, staffing levels, location and a portfolio of treatments. Further, the building is often a local landmark, easy to find in a moment of need. Community-based services, on the other hand, tend to be more dispersed and less well-embedded in the communal consciousness. They have yet to learn to project confidence, security and commitment to a better quality of life for users.

**Individual needs assessment** usually involves a specialist (or a multidisciplinary team) working with the service user (and their family) to identify their needs and how they might best be met, leading to the development of a personal care plan. In institutions, needs assessment tends to be carried out by the staff of the institution, which assesses a person's needs in the context of what the institution can offer. In good community care services, it means a complete assessment of a person's needs and life circumstance and leads to the delivery of a variety of services.

**Service capacity** is about whether there is enough supply to meet the demand for services. The existence of waiting lists and urban/rural divide in terms of service coverage may reflect a failure of strategic planning or inadequate funding. The capacity and availability of services should be assessed regularly by local authorities and other service planners and funders on the basis of a strategic area needs assessment and planning.

In community care, **choice** is a broad concept: it is not only about a choice between different providers of the same service or between different services altogether, but also about how a person is to live their life. Meanwhile, in an institution, choice may be thought of as a choice of special facilities within its walls. The view that institutions offer more choice was dismissed in the European report of 2009<sup>2</sup> which points out that institutions tend to treat all residents in the same way, restricting individual choice in favour of routine.

The transition from institutional to community care should have as a goal the improvement of service users' **quality of life**, i.e. their total well-being, including all emotional, social, and physical aspects of the individual's life. Meanwhile, in an institution, quality is often understood as a compliance with the parameters set by the regulator, such as a ratio of staff per resident or the size of a room per person. By contrast, community care focuses on the individual with their needs and wishes, offering services that are more readily adaptable to users' wishes and preferences. This makes community-based services more likely to see an individual as a whole person with emotional, social and physical needs.

Being cared for in an institution means being away from home, often in a different town or region altogether and having limited contact with the world outside, including with family and friends. It sets people apart, segregates and labels them. Community care aims to keep people in the local community at home or in a home-like environment for as long as possible, giving them the best chance of achieving full **social inclusion**. In order to succeed in this, services in the community must be coordinated and interconnected to meet both basic and complex needs.

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<sup>2</sup> Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care was drafted by a group of independent experts convened by Commissioner Vladimír Špidla in February 2009 to address the issues of institutional care reform in their complexity.  
<http://ec.europa.eu/social/BlobServlet?docId=3992&langId=en>

# GLOSSARY

There are no internationally approved definitions of ‘institutions’ nor of ‘community care’. A review of the literature reveals a number of sector-specific definitions related to disabilities or mental health. As this report covers not only these two groups but also children and older people in care, the following working definitions will apply throughout in order to aid the reader’s understanding of terms used:

## **Service user/Resident/Vulnerable person**

These are the terms used in this report to refer to the people living in institutions or in the community who need care and support in their daily life. The four main user groups discussed in ESN’s work on developing community care were: people with disabilities; people with a mental health problem; children in care; dependent older people.

## **Community-based services; community-based care; community care**

These are forms of assistance, support and care that enable people to overcome or manage whatever condition, disability or set of life circumstances they face. ‘Community-based’ refers to the idea that vulnerable people should live alongside ‘ordinary’ people in the same street, rather than be segregated from them. Furthermore, ‘community-based services’ tend to be seen as the best setting in which to empower the user to participate in society and to take control of his/her own life. In the case of children, community care is understood as “care that is as close as possible to family-based care and where the community is involved in the process of a child’s recovery. Foster and extended families are examples of community-based care”.<sup>3</sup>

<sup>3</sup> Better Care Network Toolkit and Glossary of Key Terms, available at: <http://bettercarenetwork.org/BCN/Toolkit/Glossary/index.asp>

‘**Institution**’ refers to a long-stay residence in which people live and receive care for an unspecified period of time following a medical or social assessment or a court decision. Residences usually consist of sleeping accommodation, shared bathrooms and common areas for socialising. Residents may have private rooms, shared rooms, larger dormitories or hospital-style wards. Health and social care professionals are employed by an institution to provide care to residents. Institutions may be characterised by uniformity of design, décor and routine. In relation to children with intellectual disabilities, WHO defines institution as residential facilities that:

- are isolated from the mainstream community, providing little opportunity for inclusion in normal everyday life and experiences;
- house relatively large groups of non-family members who are compelled to live together;
- result in prolonged periods of separation from the child’s family, friends and community;
- are organised according to a regimented routine that cannot respond to the individual needs and wishes of the children; and
- segregate children from the community owing to a diagnosis of disability and/or chronic illness.<sup>4</sup>

Although ‘**institution**’ is the most common name, some long-stay residences may also be called: ‘centre’, ‘boarding/special school’, ‘hospital’, ‘orphanage’, ‘medico-social home’, ‘residential care home’, ‘pension’ and many other names.

<sup>4</sup> WHO Europe, Better health, better lives: children and young people with intellectual disabilities and their families, EUR/51298/17/PP/3, November 2010, p. 4

**Institutional culture** is the notion coined by the European Ad Hoc Group on Transition from Institutional to Community Care used to define the characteristics of institutions. The group argues that external features (such as walls, gates, large secluded building) are merely ‘the most visible and not necessarily the most important in defining what is an institution’. Instead they propose to concentrate on such internal characteristics, defined as: “1) *depersonalisation* (removal of personal possessions; 2) *rigidity of routine* (fixed timetables for waking, eating and activity irrespective of personal preferences or needs); 3) *block treatment* (processing people in groups without privacy or individuality) and 4) *social distance* (symbolising the different status of staff and residents).”<sup>5</sup>

**Deinstitutionalisation/transition to community-based care** refers to a shift in the type of care provided to vulnerable people. Former (and potential) residents should be assessed and consulted and be able to live in an alternative setting that suits their needs and preferences, and in which they can receive such support as is necessary. It is “*not a series of events but a process which never ends. It is not about taking people out of buildings called institutions; it is rather a process of helping people to gain or to regain control over their lives and become socially included.*”<sup>6</sup>

**Normalisation** is the principle that people with learning disabilities should lead a life which resembles, as far as possible, the rest of society, with opportunities to have friends, live in their own homes, study, work, enjoy close relationships and pursue leisure activities<sup>7</sup>.

**Person-centred planning** is an approach to personal support developed within learning disability services which seeks to realise the aspirations of individuals by giving them control over the planning process, recognising them as experts with respect to their own lives<sup>8</sup>. It involves ‘*continual listening and learning about a person’s aspirations and working towards these with the support of family and friends.*’<sup>9</sup>

**Personalisation** means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, characteristics, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. It requires a significant transformation of adult social care so that all systems, processes, staff and services are geared up to put people first.<sup>10</sup>

<sup>5</sup> Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care was drafted by a group of independent experts convened by Commissioner Vladimír Špidla in February 2009 to address the issues of institutional care reform in their complexity.

<http://ec.europa.eu/social/BlobServlet?docId=3992&langId=en>  
<sup>6</sup> Henderson J, Short Paper on Deinstitutionalisation in the context of the Greek Reform Programme (not published)

<sup>7</sup> Baldock J., Manning N., Vickerstaff S., Social Policy, 3<sup>rd</sup> edition, Oxford University Press 2007 (p. 473)

<sup>8</sup> Ibid

<sup>9</sup> Collins Dictionary of Social Work, ed. Pierson J., Thomas M., HarperCollins Publisher 2006

<sup>10</sup> SCIE, ‘At a glance’ series no. 41 of April 2011, Personalisation briefing: Implications of the Equality Act 2010 available at:  
<http://www.scie.org.uk/publications/atagance/atagance41.asp>



# INTRODUCTION

Alongside challenges such as demographic ageing, migration, discrimination, unemployment or child poverty, the transition from an institutional to a community-based model of care remains one of the major challenges facing the European Social Model. It is a challenge compounded by a number of barriers to change:

- There is no universal definition of an 'institution'
- There are no reliable official data about the number of institutions nor about how many people live in them
- There is an assumption that institutions are only an issue in Central and Eastern Europe, where they were widespread during the Communist era.
- There is an assumption by some that institutions are a good place for 'vulnerable people' to be safe and well looked-after
- There is a view that the transition to community-based care is desirable but not achievable.

There have however been some promising attempts to overcome these barriers to change.

Recognising the difficulty of providing a universal definition of an institution, this report utilises a working definition from an influential European report that outlines three key characteristics:

- "Users are isolated from the broader community and/or compelled to live together
- Users do not have sufficient control over their lives and over decisions which affect them
- The requirements of the organisation [running the institution] tend to take

precedence over the users' individualised needs."<sup>11</sup>

Various studies provide **indicative data** on the number of people living in institutions according to categories of service users. The above-mentioned European report admits, as stated in the foreword, that "*the actual number of persons in institutional care is difficult to ascertain due to the lack of available data, but it is certainly in the millions*"<sup>12</sup>. Most data are not drawn from official statistics but gathered through 'self-reporting', which may cast doubt on their reliability. Comparisons within countries, let alone between them, are inherently difficult given differences in what data is collected and how, depending on the level of government and the sector (social, health, education) of public administration. As far as the **size of institutions** (in both 'Old' and 'New' Europe) is concerned, delegates to an ESN seminar in 2009 reported that their average size was over 120 beds.<sup>13</sup> Institutions in Northern and Western Europe may look very different: they may be purpose-built and have well-trained staff, but still – to go back to the above definition – they "*isolate users from the community*" and do "*not give them sufficient control over their lives*".

The **prejudicial view** that 'vulnerable people' (for want of a better term) are largely dependent and need to be sheltered, protected and looked after, has progressively been challenged by user associations and reforms to give users more control over their lives, including by living in their own homes. Vladimír Špidla, former European Commissioner for Employment, Social Affairs and Equal Opportunities wrote:

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<sup>11</sup> Ibid., p.8

<sup>12</sup> Ibid., p.5

<sup>13</sup> ESN Members Survey on Deinstitutionalisation and Community Care Development 2009 <http://www.esn-eu.org/get-document/index.htm?id=400>

*“For decades, the existence of such institutional care was seen as proof that society cares, that it does not leave vulnerable persons without assistance and that it provides the needy with food, shelter, clothing and treatment. But is this ... the best possible model which advanced European societies can offer ... in the 21st century?”<sup>14</sup>*

The institutional model of care is certainly about the care setting and its size but is perhaps determined by how society views people who live in institutions. However well-intentioned this view is, there is enough proof today that people can live relatively normal lives in ordinary flats or houses in ordinary streets, provided that there is sufficient investment in key services.

Despite the evidence supporting such normalisation, there are still those who believe that the well-embedded institutional model of care is simply too difficult to change. Sceptics argue that the transition is too complex and expensive to manage and that services in the community are unaffordable. In this report, we argue that deinstitutionalisation is desirable and – though challenging – it is achievable. Our report outlines what the challenges are and how they can be overcome in order to end mass social exclusion in institutions and give many more people what most of us take for granted – a life like others and with others.

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<sup>14</sup> Foreword to the Report of the Ad Hoc Group, op.cit., p.2

# Developing Community Care

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**Part I:**

*Making  
the case for  
community care*



# PART I

## Making the Case for Community Care

There is a powerful case for the transition from institutional to community care. In Part I we present four different sets of arguments supporting transition, beginning

with the most important – the voice of service users. We then review international human rights instruments and social work principles, and conclude with the economic case.

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### 1. The voice of former residents

Many testimonies of (former) residents reveal the shortcomings of an institutional model of care: they show how life in an institution is far from 'ordinary life'. Some institutions try to remedy this by doing their best for – often severely disabled – residents, offering them good care and at least some choice in terms of their activities. The negative experiences of institutional care, as presented in this section, are not necessarily universal for all former residents. Indeed, some may treasure their memories of a particularly caring member of staff or of a friendship that developed with another resident. Even modern institutions with good facilities, decent fittings and well-trained staff cannot offer the 'normality' of shopping, cooking, going out and spending their time as they wish, in brief: to live like others and with others.

This section uses testimonies of former residents to illustrate the difference between an ordinary life and life in an institution. What follows will appear for some countries to reflect the situation in institutions twenty or thirty years ago; for others, it may be a more recent past or even present-day reality in some parts of the country or for some service sectors.

The testimony of a former resident of a Dutch institution for people with intellectual disabilities shows what this means in reality

and how remote a life in institution is from a 'normal life':

*"When I came to Vijvervreugd, it felt just like being in a hospital, but I was not sick at all. The personnel all wore the same white uniform. I slept in a dormitory with 11 others. We didn't have a place for ourselves and spent the whole day as a group. What I found the worst was taking a bath all together. I am rather prudish, but still everyone had to take a bath every day. We all stood naked waiting for our turn. And then you had to put on your pyjamas, at five o'clock in the afternoon, imagine, I was twenty years of age."<sup>15</sup>*

Today this former resident lives on her own and works in a flower shop.

This account illustrates not only the difference between 'normal' and 'institutional' life but also points us to the importance of independent, individual needs assessment. It is clear that this young woman did not need to be cared for in an institution given that she is able to manage on her own with some support. This may indicate that the person responsible for referring her to Vijvervreugd did not look at the range of her abilities, at her wishes and needs but focused entirely on the fact that she had a learning disability which qualified her for admission to that institution.

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<sup>15</sup> Van Loon, J., & Van Hove, G. (2001). *Emancipation and self-determination of people with learning disabilities and downsizing institutional care*. *Disability & Society*, 16(2), 233-254, available at: <http://www.arduin.nl/english/index.asp>

The issue of individual needs assessment is discussed in more detail in Part III.

Institutional care is often criticised for disempowering users. A Bulgarian resident, asked about her life in an institution, responded:

*“The ladies (social workers) know the things you ask me about my personal documents. They are in charge for this....I do not know whether we will go again on a trip to the seaside. Maybe if the ladies decide we will go...the ladies tell us when there are concerts in the city and sometimes they bring us there...”*<sup>16</sup>

A former director of social services in England recalls his experience of institutions for people with disabilities:

*“Users were always called ‘boys’ or ‘girls’ and when addressed individually, it was never a proper name, always a diminutive like ‘Teddy’ or ‘Johnny’. The staff were certainly warm and caring, but they treated users like small children and not adults with potential.”*

For children and young people, the experience of institutional care is often traumatic, leaving them with a feeling of shame or anger. One young Romanian says: *“It was not safe. The older guys used to beat me and make me do humiliating jobs”*<sup>17</sup>. Another says: *“It was really hard going to school each day knowing that I was going to be teased and tormented simply because I lived in an orphanage.”*<sup>18</sup>

<sup>16</sup> ESSC, 6-8 July 2011 Warsaw, Workshop presentation by the European Union Agency for Fundamental Rights (FRA) available at: <https://esn-conference.org/sites/default/files/FRA%20English.pdf>

<sup>17</sup> UNICEF Country Profile ‘Leaving Institutional Care – Romania’ available at <http://www.unicef-irc.org/research/ESP/youth/r12inst.pdf>

<sup>18</sup> Smith G. P., *A sense of self and shame*, academic paper submitted in 2011 to the Australian Sociological Association, available at <http://www.tasa.org.au/uploads/2011/01/Smith-Gregory.pdf>

Children and young people who were in institutional care also speak of being lonely and invisible. In the words of a child from Moldova:

*“When we are at home with our grandparents we feel loved. Here, I don’t feel loved. Other children are not very good friends with me. I prefer being at home, talking to my sisters and having fun.”*<sup>19</sup>

Unsurprisingly, older people too express a preference to stay at home. Likewise, almost 90% of respondents in one European survey felt that social and health care systems should help older people to remain in their homes for as long as possible.<sup>20</sup> Whereas people agree that at some point in life it may be necessary to live in a care home or a nursing home, they mostly dread the idea of having to leave their home, neighbours and friends when they still can go about their business independently. *“It’s like being in a prison sometimes, being in a care home, except that it’s carpeted,”* says one older person from England.<sup>21</sup>

Institutions may well provide physical security, food and shelter, but they struggle to offer the sense of well-being that stemmed from being included in society, loved and valued by friends and relatives. It is striking how often vulnerable people compare institutions to prisons and how they long for a ‘normal life’ - at home and not in a home. As one former resident said, *“even a piece of bread tastes nicer at home.”*<sup>22</sup>

<sup>19</sup> Quoted in Lumos ‘Our news and views’ section, *Why celebrations are better at home* published online on 31 May 2011, available at <http://www.lumos.org.uk/news.php/392/why-celebrations-are-better-at-home>

<sup>20</sup> European Foundation for the Improvement of Living and Working Conditions. *Health and care in an enlarged Europe*. Luxembourg, Office for Official Publications of the European Communities, 2004.

<sup>21</sup> Shaping Our Lives consultation for Cumbria County Council/Primary Care Trust: *Assessing future housing need for older people* available at:

[www.cumbria.gov.uk/elibrary/view.asp?ID=36288](http://www.cumbria.gov.uk/elibrary/view.asp?ID=36288)

<sup>22</sup> *Why celebrations are better at home*, op.cit

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## 2. The social work case

Social work is based on respect for the inherent worth and dignity of all people, and from this follows an approach that empowers those in need to live independent and fulfilling lives. The 'Ethics in Social Work, Statement of Principles'<sup>23</sup> adopted by the International Federation of Social Workers (IFSW) in 2001 states that "*social workers should focus on the strengths of all individuals, groups and communities and thus promote their empowerment.*" They also endorse freedom of choice:

*"Social workers should respect and promote people's right to make their own choices and decisions, irrespective of their values and life choices, provided this does not threaten the rights and legitimate interests of others."*

If a person is living in an institution, typically the rigidity of routine does not allow them to make their own choices, e.g. about when to get up, wash and when and what to eat.

Self-determination and choice are the key social work values which should guide the design and delivery of social services. Yannis Vardakastanis, President of the European Disability Forum, who spoke at ESN's European Social Services Conference in 2011<sup>24</sup>, believes that:

*"Freedom of choice is the holiest right. If a person is not able to exercise this right, (s)he is in captivity. It is a form of social slavery"*<sup>25</sup>.

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<sup>23</sup> IFSW (International Federation of Social Work), 'Ethics in Social Work', Statement of Principles, approved at the General Meetings of the International Federation of Social Workers and the International Association of Schools of Social Work in Adelaide, Australia, October 2004, available at: <http://www.ifsw.org/f38000032.html>

<sup>24</sup> ESSC, 6-8 July 2011 Warsaw, programme and all presentations are available at: <http://esn-conference.org/programme-warsaw>

<sup>25</sup> ESSC, 6-8 July 2011 Warsaw, Speech by Yannis Vardakastanis, presented during the plenary session 'Towards Community Care' available at: [https://esn-conference.org/sites/default/files/Vardakastanis%20Speech\\_0.pdf](https://esn-conference.org/sites/default/files/Vardakastanis%20Speech_0.pdf)

Vardakastanis likened institutions to prisons and called compulsory institutionalisation a "*flagrant violation of human rights*". He called on users and service providers – public and private – to work together and bring about change.

The British Code of Ethics of the National Association of Social Workers also highlights the principle to recognise the central importance of human relationship. This means that an ethical social worker "*engages people as partners in the ... process and seeks to strengthen relationships among people to promote, restore, maintain and enhance the well-being of individuals, families and communities*".<sup>26</sup> This broad commitment to nourish contacts between users and the wider community can be easily compromised in an institutional care setting where users are separated from others.

Care in the community, by contrast, creates more opportunities for people to develop meaningful relationships and be included in society. Although social work has undergone many changes in the second half of the 20<sup>th</sup> century in terms of organisational context or the nature of the social and political environment, its key principles have remained constant. In the 21<sup>st</sup> century, they 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.

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<sup>26</sup> National Association of Social Workers, Code of Ethics, approved in 1996 and revised by the 2008 NASW Delegate Assembly, available at: <http://www.socialworkers.org/pubs/code/code.asp>

### 3. The human rights case

Just like the voice of former residents and the values of social work, international treaties and conventions clearly favour community-based over institutional care. The wide array of international, European and national legal acts and declarations aim to prevent segregation, guarantee equal opportunities and safeguard the human rights of the most vulnerable people. They emphasise that every person, whether young or old, whatever disability or illness they may have, should enjoy the same rights and responsibilities: these are not negotiable and cannot be restricted or removed due to arbitrary criteria. This section brings together some of these rights and presents them in an accessible table, allowing the comparison between different user groups and documents.

Children	Disability (including mental health)	Older People <sup>27</sup>
<p>Respect</p> <p>EU Charter of Fundamental Rights<sup>28</sup> art. 24:</p> <p>“In all actions relating to children, whether taken by public authorities or private institutions, the child's best interests must be a primary consideration.”</p> <p>“All decisions [...] should respect the child's right to be consulted and to have his/her views duly taken into account in accordance with his/her evolving capacities, and on the basis of his/her access to all necessary information.”</p>	<p>EU Charter of Fundamental Rights art. 26:</p> <p>“The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.”</p>	<p>EU Charter of Fundamental Rights art. 25:</p> <p>“The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.”</p>

<sup>27</sup> For more information about the rights of older people and Madrid International Plan of Action on Ageing (including Guiding Framework and Toolkit for practitioners and policy-makers) read: [http://www.un.org/ageing/documents/building\\_natl\\_capacity/guiding.pdf](http://www.un.org/ageing/documents/building_natl_capacity/guiding.pdf)

<sup>28</sup> Charter of Fundamental Rights of the European Union published on the 18 December 2000 in the Official Journal of the European Communities (C 364/1) available at: [http://www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf)

Children	Disability (including mental health)	Older People
<p>Choice</p> <p>UN Guidelines for the Alternative Care of Children<sup>29</sup>, guideline 93:</p> <p>“All carers should promote and encourage children and young people to develop and exercise informed choices, taking account of acceptable risks and the child’s age and his/her evolving capacities.”</p>	<p>UN Convention on the Rights of People with Disabilities<sup>30</sup>, art. 3:</p> <p>“The principles of the present Convention shall be: (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.”</p>	<p>UN Principles for Older Persons<sup>31</sup>, principle 14:</p> <p>“Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.”</p>
<p>Place to live</p> <p>UN Guidelines, guideline 22:</p> <p>“...where large residential care facilities (institutions) remain, alternatives should be developed...”</p> <p>“Decisions regarding the establishment of, or permission to establish, new residential care facilities, whether public or private, should take full account of this deinstitutionalization objective and strategy.”</p>	<p>UNCRPD art. 19:</p> <p>“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.”</p>	<p>UN Principles for Older Persons, principle 5:</p> <p>“Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.”</p>

<sup>29</sup> Guidelines for the Alternative Care of Children; Resolution adopted by the General Assembly (A/64/434) on the 24th February 2010, available at: <http://www.europe.ohchr.org/Documents/UN%20Docs/Un%20Guidelines%20for%20the%20Alternative%20Care%20of%20Children.pdf>

<sup>30</sup> Convention on the Rights of Persons with Disabilities (UNCRPD) and Optional Protocol, adopted on 13 December 2006 by the United Nations General Assembly, available at: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

<sup>31</sup> Resolution of the General Assembly on the Implementation of the International Plan of Action on Ageing and related activities and Adoption of the UN Principles for Older Persons (A/RES/46/91) adopted on the 16 December 1991, available at: <http://www.un.org/documents/ga/res/46/a46r091.htm>



Children	Disability (including mental health)	Older People
<p>Participation</p> <p>UN Guidelines, guideline 131:</p> <p>“Throughout the period of care (agencies and facilities) should systematically aim at preparing children to assume self-reliance and to integrate fully in the community, notably through the acquisition of social and life skills...”</p> <p>UN Convention on the Rights of the Child<sup>32</sup>, art. 23:</p> <p>“States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.”</p>	<p>UNCRPD art. 26:</p> <p>“States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.”</p>	<p>UN Principles for Older Persons, principle 7:</p> <p>“Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.”</p>
<p>Protection</p> <p>UNCRC art. 20:</p> <p>“A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.”</p>	<p>UNCRPD art. 16:</p> <p>States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services.”</p>	<p>UN Principles for Older Persons principle 10:</p> <p>“Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.”</p>

<sup>32</sup> Convention on the Rights of the Child (UNCRC), adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989, available at: <http://www2.ohchr.org/english/law/crc.htm>

## 4. Understanding the economics

Many policy-makers and service providers believe that only large institutions are capable of producing the economies of scale required for care to be affordable. The lack of a universally accepted definition of an institution, the breadth of what constitutes community care and the lack of reliable data all create difficulties in producing comparative cost analyses. There is little research in this area, but some clear findings emerge from existing literature.<sup>33</sup>

Good community care should not be regarded as a cheap alternative: it requires adequate infrastructure, adequately trained staff and a political, professional and administrative commitment to a better model of care. Closing down large institutions may not immediately save money, especially where community-based services are yet to be established. The costs of transition comprise 'both the initial investment in community-based services and the dual costs of running parallel services for a number of years'.<sup>34</sup>

Community care, whilst not cheaper, is not necessarily more expensive than institutional care. The cost argument varies across different user groups. The evidence suggests that institutional care for children and young people is not only the worst but also an expensive form of care. An EU-funded study<sup>35</sup> estimates institutional care to be three times

more expensive than family foster care for disabled and non-disabled children alike. Measures to support the family are said to be ten times less expensive than care in institutions.<sup>36</sup> This may however not be true for some highly specialised foster services in Western European countries, which tend to be very expensive but also highly effective in caring for children that could not be supported by their own family.

Meanwhile, in mental health services, community care is not necessarily more expensive (adjusting for needs) and has been found to be cheaper in British and American studies<sup>37</sup>, partially motivating the launch of deinstitutionalisation reforms in both countries. As in general health services, the cost of running fully staffed hospitals is simply too high to make them a default form of care. In intellectual disability services, community care appears to be slightly more expensive.<sup>38</sup> This is mainly because congregated care settings tend to employ fewer staff support per resident. This ratio may not be so relevant for people with less severe disabilities but for those with severe and profound disabilities, less staff support is likely to mean poorer quality of life<sup>39</sup>.

<sup>33</sup> With the exceptions of Martin Knapp and David McDaid's work at King's College and LSE and the Kent University study DECLOC, there is very little research in this area available. Most authors quote Knapp and McDaid's publications or DECLOC report. This section of the report is also based on these sources.

<sup>34</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2 Main Report, p. 79, Canterbury: Tizard Centre, University of Kent, available at: [http://www.kent.ac.uk/tizard/research/DECL\\_network/document/s/DECLOC\\_Volume\\_2\\_Report\\_for\\_Web.pdf](http://www.kent.ac.uk/tizard/research/DECL_network/document/s/DECLOC_Volume_2_Report_for_Web.pdf)

<sup>35</sup> *De-institutionalising and Transforming Children's Services - A Guide to Good Practice*, published 2007, DG Justice and Home Affairs in collaboration with WHO Regional Office for Europe and the University of Birmingham, UK, available at [http://www.crin.org/docs/Deinstitutionaliation\\_Manual\\_Daphne\\_Prog\\_et\\_al.pdf](http://www.crin.org/docs/Deinstitutionaliation_Manual_Daphne_Prog_et_al.pdf)

<sup>36</sup> *De-institutionalisation - Ensuring Better Outcomes for Individual Children*, PowerPoint presentation by Georgette Mulheir, 2010

<sup>37</sup> WHO, *What are the arguments for community-based mental health care?*, Health Evidence Network (HEN) synthesis report, available at:

[http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0019/74710/E82976.pdf](http://www.euro.who.int/__data/assets/pdf_file/0019/74710/E82976.pdf)

<sup>38</sup> ESSC, 6-8 July 2011 Warsaw, Presentation by Martin Knapp during the plenary session 'Towards Community Care' available at [https://esn-conference.org/sites/default/files/Martin%20Knapp\\_0.pdf](https://esn-conference.org/sites/default/files/Martin%20Knapp_0.pdf)

<sup>39</sup> Mansell, J., Beadle-Brown, J. *Cost-effectiveness of community living for people with intellectual disabilities: an international perspective*, paper given at the National Disability Authority Annual Conference, Dublin 6 October 2009, available at:

[http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/C60FC2E1F2A530068025768E003F108E/\\$File/prof\\_jim\\_mansell\\_proceedings.htm](http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/C60FC2E1F2A530068025768E003F108E/$File/prof_jim_mansell_proceedings.htm)

When drawing comparisons, it is important to compare users with similar needs. The DECLOC report quotes studies from Germany and the UK comparing costs and outcomes for people with similar needs<sup>40</sup> in independent living compared with fully staffed group homes. Interestingly, the total cost of care in the former was almost three times lower €442 vs. €1256.<sup>41</sup>

In the field of disability, the studies suggest that care is most expensive for those with the most complex needs and that for those users an institution may well offer care at a lower cost. Unfortunately, this observation can affect care choices, as happens, for example, in Germany:

*“If it is considered cheaper to put people in institutional care, then they have no legal right to resist that”<sup>42</sup>.*

In general however, if costs and quality of life are both considered community care emerges as more cost-effective. Where community care is significantly more expensive, it is correlated with much better individual outcomes, i.e. better quality of life for people who would otherwise have been in institutions. In the above UK study, semi-independent living scored better on the index of lifestyle advantages, offering people more freedom, greater choice and self-determination, even though some risks were identified in terms of residents' welfare and health. In another study of the closure of two North London psychiatric hospitals, patients *“were enjoying a quality of life at least as good as in hospital one and five years after*

*discharge” and “strongly preferred community living to hospital.”<sup>43</sup>*

Deinstitutionalisation is most cost-effective when recognised as a mainstream policy and implemented across the system. Speaking at the European Social Services Conference in Warsaw in 2011, Professor Knapp said:

*“Deinstitutionalisation is most successful if located within other policy efforts such as personalisation, self-direction, carer support, anti-stigma efforts, access to employment, social participation, integrated care and others”<sup>44</sup>.*

It is also worth noting that deinstitutionalisation, whilst requiring investment in the short and medium term, can save money in the longer term. The ‘cashable benefits’ of deinstitutionalisation (i.e. the savings arising from it) may fall across different budgets. It is important to recognise the savings made in the broader system rather than concentrating on each service income and expenditure.

These savings can easily go unnoticed if *“professional rivalry, myopic budget protection, ignorance, indifference or simply stultifying bureaucracy”* discourage a wide perspective.<sup>45</sup> Policy makers and practitioners must be aware of these risk factors in order positively to assess the benefits of involving health, housing, employment, education and childcare services in a well-managed deinstitutionalisation process. It may be that one or more agency will need to spend more of its own resources in order for another agency to achieve savings or for the system as a whole to achieve better outcomes.

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<sup>40</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007), Volume 2: Main Report, op.cit. p.71

<sup>41</sup> Originally expressed in pound sterling at 2003/2004 price level £379 vs. £1076 per week

<sup>42</sup> Academic Network of European Disability experts (ANED) Synthesis Report The Implementation of Policies Supporting Independent Living for Disabled People in Europe 2010 (VT/2007/005), p.24, available at: <http://www.disability-europe.net/content/aned/media/ANED-Task%205%20Independent%20Living%20Synthesis%20Report%2014.01.10.pdf>

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<sup>43</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007), Volume 2: Main Report, op.cit. p.65

<sup>44</sup> See ESN newsletter, July 2011 issue, available at: <http://esn-eu.org/e-news-jul11-dcc-session>

<sup>45</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007), Volume 2: Main Report, op.cit., p. 88

Savings may also follow the introduction of independent individual needs assessment mechanisms. A review of all needs assessment documents (if they exist) may prove that some users don't need a residential type of service at all or that the reason why they needed it in the first place is no longer valid. Helping those people to recover their independence will remove them from the care system and create savings which will in turn compensate for a higher cost of quality community care for those who need continuous support of the services.

Undoubtedly, the analysis of expenditure on institutional care and on support for people to live in the community or independently is *“an area fraught with difficulties and open to many nuances of interpretation.”*<sup>46</sup>

There is clearly a need for more and better data and research into the economics of social policy interventions. However, given the improvement in quality of life of their fellow citizens, neither policy-makers nor the general public should be discouraged by the costs of the transition to community-based care:

*“There is no evidence that community-based models of care are inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and comparable quality of care. Community-based systems of independent and supported living, when properly set up and managed, should deliver better outcomes than institutions.”*<sup>47</sup>

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<sup>46</sup> ANED Synthesis report, op.cit., p.22

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<sup>47</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) Volume 1: Executive Summary, p.7. Canterbury: Tizard Centre, University of Kent, available at: [http://www.kent.ac.uk/tizard/research/DECL\\_network/documents/DECLOC\\_Volume\\_1\\_Exec\\_Summary\\_final.pdf](http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_1_Exec_Summary_final.pdf)

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## PART I: Conclusions

Is the transition from institutional to community-based care a change worth making? This part of the report leaves no doubt that it is the right decision – and long overdue. Users tell us about their preference for a life “like others and with others”, in the words of the one of the members of ESN’s working group. Social work professionals, mindful of their code of ethics, understand that respect, dignity, choice and empowerment can be better observed in the community care setting. Human right lawyers and activists remind us that the EU Fundamental Rights Charter and several UN Conventions are in place to protect the right of vulnerable people

to decide where they want to live and to receive adequate level of support. Finally, economists convincingly argue that community care is simply a better option from a cost-effectiveness point of view, giving better value for money and an improved quality of life for people using services.

These varied and rich arguments make it clear that the transition to community care is a decision that should no longer be delayed. Once this realisation is made, the second part of this report helps to understand the first steps.

Notes:

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# Developing Community Care

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**Part II:**

*Making the  
first steps  
towards  
community care*



## PART II

# Making the first steps towards community care

Deinstitutionalisation requires a vision for change and the leadership to bring it about, combined with the participation of all those

affected. This part of the report explores the key elements required to launch a deinstitutionalisation reform.

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### 1. Vision and Leadership

Deinstitutionalisation is not a simple change from large to small care units – it is about shifting the focus of care from structures to people and their needs. Bringing about this change first and foremost requires a vision and leadership to take it further. A vision provides guidance and serves as “*a signpost pointing the way for all who need to understand what the organisation is and where it intends to go.*”<sup>48</sup>

A vision for deinstitutionalisation means making a mental picture of a community where people no longer live in institutions but receive care and support at home or in a home-like environment. A clear vision should stimulate continuous improvement and new ways of designing and delivering services. It means moving not just away from the setting but also from the culture of institutions towards community-based services that promote self-determination, dignity and wellbeing for individuals.

A lack of vision was identified in the DECLOC report as one of the major obstacles to the transition to community care. This is often combined with a pessimistic view as to the ability of some individuals to lead independent or semi-independent lives.

To deliver a vision requires a transformation of how we think about services, how they are delivered and what they should achieve. This is the role of a leader. ESN’s chief executive, John Halloran, observes:

*“Leadership is the capacity to translate vision into reality”.*

What constitutes effective leadership? According to an ESN member organisation in Scotland, effective leadership in social services comprises the following elements:

- *“looking to the future, planning ahead and anticipating future demands;*
- *communicating a sense of direction, inspiring and uniting people with a shared sense of commitment;*
- *adapting leadership styles to suit particular circumstances;*
- *developing a high performing senior management team;*
- *driving change and managing communication effectively during periods of change.”*<sup>49</sup>

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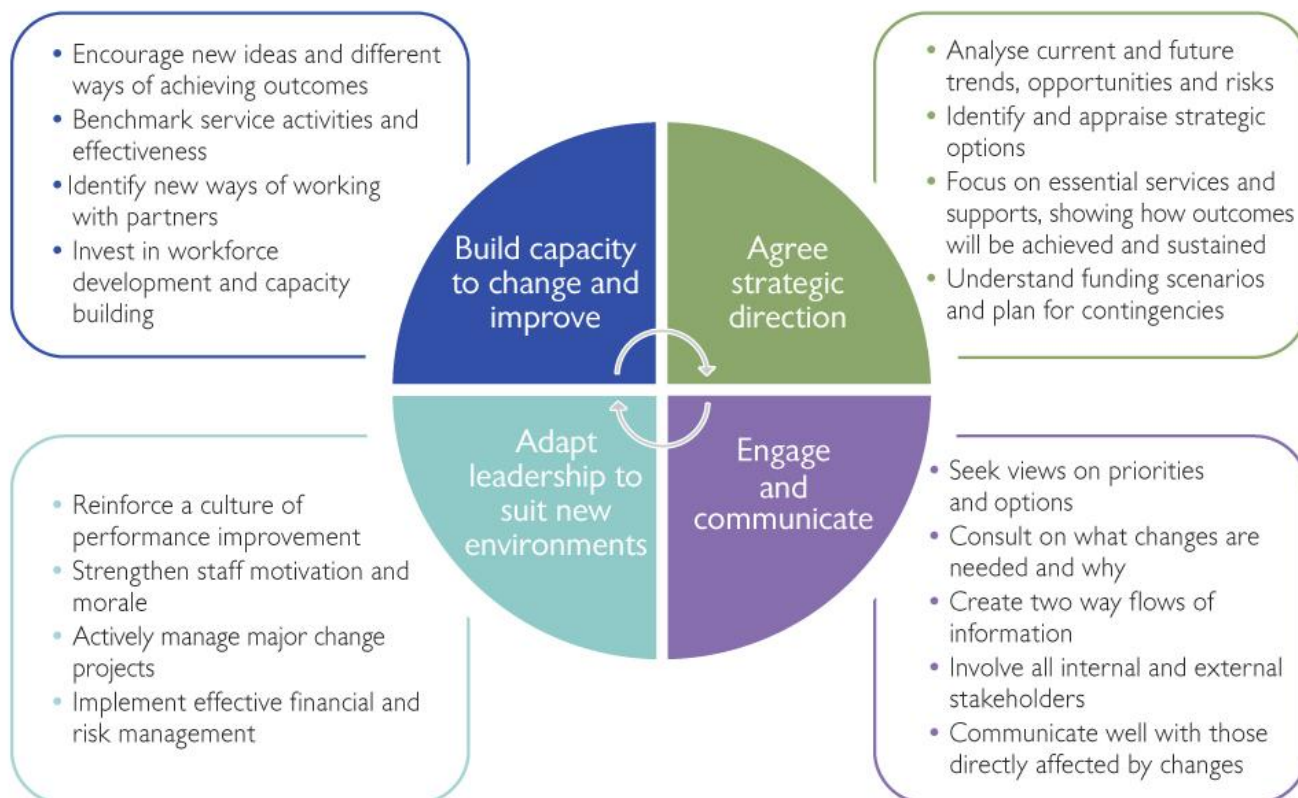
<sup>48</sup> Nanus, B. (1992). *Visionary leadership: Creating a compelling sense of direction for your organization*. San Francisco: Jossey-Bass.

<sup>49</sup> Guide to Leadership - Taking a closer look at leadership in social work services (2010), study commissioned by the Scottish Government from the Social Work Inspection Agency, available at: <http://www.scotland.gov.uk/Publications/2010/09/02163616/2>



These qualities, presented as a diagram<sup>50</sup> (below) offer a good visualisation of what is needed to lead improvement and change in social work services:

In the opinion of Julie Beadle-Brown, co-author of the DECLOC study, directors of social services in local and regional government are well-placed to assume leadership in deinstitutionalisation reforms. Speaking at an ESN seminar in Warsaw in 2009, she assured the delegates: *“If you have the vision, you’ll find a way.”*<sup>51</sup>



<sup>50</sup> Ibid.

<sup>51</sup> ESN Seminar 'Towards Community Care', 8-9 May 2009 Warsaw, Presentation by Julie Beadle-Brown, available at <http://www.esn-eu.org/get-document/index.htm?id=258>

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## 2. Funding

Comparative analyses on the cost-effectiveness of community versus institutional care suggests that community-based services do not necessarily cost more and that quality of life and satisfaction in those services tend to be higher.

In the initial period the cost of establishing new services while maintaining old ones may be significant. These transitional costs may include both capital investment in new facilities as a hub for a range of community-based interventions and investment in retraining staff for community care. This requires the commitment of additional funds for the first period.

The first step in developing the financial part of a deinstitutionalisation strategy should be to assess the costs of running existing institutions. This is arguably the most difficult part since institutions' budgets may be still based on historic charitable legacies or government grants; in many cases, a budget will only have risen by inflation. In some countries, institutions are paid by bed occupancy, which creates a strong incentive to work at maximum capacity (i.e. to keep people in institutions or accept new residents). A study by the Irish government revealed astonishing differences in the cost of institutional care for persons with a disability. Institutions of similar size, profile of users and quality of care in Ireland can charge between 37 and 240 000 euro per person per year.<sup>52</sup>

Establishing real expenditure may also prove difficult as funding is drawn from different sources (e.g. health insurance or social security schemes) and various public authorities. To succeed, this initial exercise

requires the commitment of all relevant funders to pool their funding into one single common budget in the future, supervised by the authority responsible for community-based alternatives. This should improve financial transparency and enable coherent strategic service planning and development. Such a budget reallocation may meet with opposition from organisations that may lose a portion of their budget.

Even if budget reallocation for community care development is successfully negotiated, the budget may not be sufficient to cover all the costs of transition. Decision-makers may therefore wish to consider the following options to secure additional resources:

- Selling the institution's building or land;
- Applying for special funds from central, regional or local government;
- Seeking support from philanthropic organisations or individuals;
- Approaching international donor organisations (World Bank, Open Society Institute, etc.);
- Applying for EU structural funds (ESF and ERDF).

The first option may be complicated by the question of ownership. In many Central and Eastern European states the largest institutions occupy castles or houses confiscated from local aristocratic families during the Communist era. The property dispute may need to be resolved first if descendants of former owners have a claim.

In some countries, meanwhile, large institutions are financed directly from the central budget, even if nominally the responsibility lies with the local authority. Even if the budget is reallocated to a municipality, the central administration may choose to keep the estate and use it for other

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<sup>52</sup> As reported by Christy Lynch at the EASPD seminar 'Deinstitutionalisation in Western European countries' held on the 3-4<sup>th</sup> October 2011 in Brussels.

purposes. Unfortunately, the 2008 crisis led to a significant fall in property prices across Europe. Municipalities willing (and able) to sell former institutions may find that there are no buyers or that the price offered is not competitive, especially if a property is in the countryside far from local amenities, businesses and residential areas.

EU structural funds may prove useful here. It is worth noting that the draft proposals for ESF and ERDF regulations covering the period 2014–2020 specifically mention the transition to community care as eligible for funding. It remains to be seen how many EU Member States will include this opportunity in their operational programmes, to be agreed with the European Commission. It seems, however, that the ratification of the UN Convention on the Rights of People with Disabilities by the EU, in particular its article 19 (the right to live in the community) has helped to place the transition to community care firmly on the agenda.

The transitional period when both institutional and community services are running should be limited to provide a clear and realistic deadline for the closure of institutions. The difficulty is in assessing how long it would take a community-based service to become established and able to serve former residents. The examples of rushed deinstitutionalisation in the US in the 1960s or in Romania just before the EU accession had a negative impact on the wellbeing of users and local communities. At the same time, maintaining parallel systems for too long risks draining financial resources and installing a two-tier system in which community care is offered to some while institutions are offered to those judged less able.

The creation of temporary solutions is also a potential difficulty in that they may become permanent over time. Some countries choose to invest in ‘half-way houses’ where users may live for a limited period to learn the basic skills necessary for (semi-)independent living and gain confidence. However, if community care services and adequate housing are not developed in time half-way houses may themselves become institutions. This was the case in Latvia, for example, where temporary accommodation was built in the grounds of six large institutions<sup>53</sup> and turned to be a long-term residence where people were still isolated from the community around.

Finally, the experience of the American deinstitutionalisation process highlights the advantage of the ‘money follows the user’ principle. This is only possible when the real cost of care is known and users’ needs carefully assessed (see Part III), but once these two conditions are fulfilled, tying money to the person helps to shift the focus from the needs of the system to the needs of the individual, paving the way for personal budgets. This principle may also reduce the financial incentives for local authorities to ‘park’ vulnerable people away in institutions funded by the central or regional government.<sup>54</sup>

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<sup>53</sup> *Wasted Time, Wasted Money, Wasted Lives ... A Wasted Opportunity?* European Coalition for Community Living, Focus Report 2010, available at: <http://community-living.info/documents/ECCL-StructuralFundsReport-final-WEB.pdf>

<sup>54</sup> Tobis, D. *Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union*, World Bank 2000, available at: <http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172671461088/MovingFromResTobis.pdf>

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### 3. Involving users, relatives, staff and communities

The transition to community-based care cannot be successful without the involvement of users, their families and the community in which they are to live. The European Ad Hoc report contains a Basic Common Principle for the transition from institutional to community-based care:

*“Users (and their families) should be full partners in the transition process. They should be actively involved and consulted in the development, delivery and evaluation of the services they receive.”*

It is important to be aware that any of these stakeholders may initially oppose deinstitutionalisation, but can be won round when they see how well it works.

Residents’ parents play a key role in making or breaking deinstitutionalisation projects. In Sweden, parents’ associations were at the forefront of the battle against institutions. Their shared belief in the ‘normalisation’ principle and growing awareness of the poor quality of life their children (even as adults) faced in institutions led them to campaign for alternative forms of care. A Swedish ESN member remembers their impact well:

*“They made us all realise that institutional care is not compatible with a Swedish way of life, where everyone is a valued member of their community, with rights and responsibilities.”*

However, residents’ parents and family members, long dependent on the permanence of an institution, may greet transition with suspicion. An influential American organisation, ‘Voice of the Retarded’ is an example of a small yet well-funded association of parents advocating against deinstitutionalisation. Their argument is that not everyone is capable of living in the community and not every family should carry the burden of care of a vulnerable relative. In

their legislative and awareness-raising campaigns they use economic arguments and draw attention to incidents of abuse and neglect in community care services.<sup>55</sup>

In Central and Eastern Europe, families may fear that the dismantling of the institutional care system will not be coupled with an extensive network of community care, leaving them with no option but to take on the role of permanent carers without support. Their fear may be compounded by the financial impact that follows from giving up (full-time) work in order to take on a caring role.

A Canadian literature review on deinstitutionalisation of people with disabilities, suggests that families may need time to build trust in the new care model and be persuaded of its benefits:

*“Family members are often initially against deinstitutionalisation, but they eventually become reconciled and may even become very supportive of community living. Indeed, family members contact their relatives much more frequently after deinstitutionalisation, and the frequency of contacts remains higher even after several years of placement in the community.”<sup>56</sup>*

People living in institutions may themselves also initially be opposed to deinstitutionalisation. Many might have lived all their lives within its walls so the institution may be the only world they know and understand. The idea of leaving the security and predictability of an institution to face the unknown may not necessarily be appealing to

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<sup>55</sup>Voice of the Retarded website:

<http://www.vor.net/images/AbuseandNeglect.pdf>

<sup>56</sup>Lemay R., *Deinstitutionalization of People With Developmental Disabilities: A Review of the Literature* [in:] Canadian Journal Of Community Mental Health Vol. 28 No. 1, Spring 2009, available at <http://www.turningforward.org/documents/Lemay2009-Deinstitutionalization.pdf>

all users. This too has implications for the way the transition is prepared:

*“Users need to be provided with appropriate information in a manner which they can understand. Where necessary, they should have support in decision-making through a person of their choice. The specific needs and requirements of each individual should be respected.”<sup>57</sup>*

Service users can however be the ones who break the circle of exclusion and fight for their right to be included in society. John Evans, President of Independent Living, spent years convincing authorities to let him and his peers leave an institution and use their individual care budget to pay for services they needed in the community. Evans, interviewed in the UK newspaper ‘The Guardian’ in 2008, spoke about his experience:

*“I was always independent, so [to end up in a care home] to me represented imprisonment. I was taken away from my roots, my family, my social contacts, everything.”<sup>58</sup>*

He set up a group called ‘Project 81’ and over a period of years they managed to convince their institutional provider and local authority to trust them with the money, long before direct payments were introduced in 1997. As in John Evans’ case, other successful examples of deinstitutionalisation clearly emphasise the importance of involving service users in the transition from institutional to community care. Users can participate in evaluation and feedback, as members of management boards or advisory groups of people with disabilities and in making decisions for themselves. Such active participation stimulates community care development and firmly places users at the heart of the process.

<sup>57</sup> Report of the Ad Hoc Expert Group, op.cit., p.19

<sup>58</sup> Brindle D., *Tireless champion of autonomy*, published in Guardian on 22 October 2008, available at: <http://www.guardian.co.uk/society/2008/oct/21/john-evans>

The care workforce needs to be taken into account as well. Used to a certain status that comes with working in a large institution, they may not immediately be in favour. ESN members report that when political decisions to close institutions in their municipalities or regions were made, staff of institutions were among the main opponents. Winning everyone over was not always possible, but a significant majority of staff come round having been offered opportunities to retrain for community care.

The skills and characteristics needed to work in the community differ from those necessary for institutional care setting. This needs to be taken into account throughout the recruitment process in order to avoid the replication of an institutional culture. Not every former employee of an institution will be able to learn the new skills, so a certain amount of staff turnover is to be expected. This may create new opportunities for those who had not previously considered a career in the care sector. The EU structural funds may be particularly useful in such cases. European Social Fund grants can be obtained to fund the full cost of staff retraining, giving employees a chance to continue their professional career in the community or move to another sector.

The local community, i.e. the neighbours, business and civil society groups around where former residents are likely to live, is another key element in successful transition. An open and accepting community can greatly help residents grow more confident and be more integrated. A community may be unfamiliar with a particular type of disability leading to some doubt or caution in accepting the person, creating worry about the safety or quality of life of the inhabitants. In the case of mental illness, as colourfully stated by a delegate to an EU conference, *“nobody wants a crazy neighbour.”*

This reluctance to accept certain people as neighbours can partly be explained by a general lack of awareness or experience in dealing with vulnerable people. The director of a community mental health service in Brighton (UK) recalls its early days:

*“When we opened our premises over 20 years ago, local people were unhappy about it. Today I can proudly say that we have strong links with the community and our services are accessed by users and non-users alike”.*

Once the local population saw that users were not left on their own and that there were effective services set up in the neighbourhood, they grew familiar with the group and forgot their initial opposition.

Local communities can also actively oppose deinstitutionalisation when it threatens their economic well-being. In areas where a large institution is the only employer, people fear its closure. This is the case of the town of Legnickie Pole in South-West Poland, where a 450-bed institution for women with intellectual disabilities is the only employer apart from the town hall and every local family has a relative working there. There are currently no plans to close this institution down nor to reduce its capacity.

The closure of an institution brings questions about where a former resident's (new) home is to be: is it their place of birth, where their close family live, the nearest town or village to the institution, or somewhere completely new? Besides being a major life decision for someone, there may be economic implications for the funder of the (new) community care system or administrative conflicts over official residency. A degree of common sense coupled with readiness to find a compromise should help the authorities and the service user together to reach a decision.

In order to bring the local people on board, it is important to create a “*culture of cooperation, trust and open discussion where all relevant participants and groups are involved*”<sup>59</sup> from the very beginning. The European Coalition for Community Living in its guidelines for successful transition to community care proposes the following rules to improve communities' involvement:

1. *“Keep it simple – it does not need to be a lengthy and complicated exercise. Use simple tools and common sense.*
2. *Clarify jargon at the start – avoid jargon or technical terms as much as possible. But if you have to use them, explain what you mean by them. Words such as deinstitutionalisation, community living etc., are widely used in policy documents, but people might mean different things by them.*
3. *Make your values and assumptions clear from the beginning of the process.*
4. *Bring in people with different backgrounds, skills and expertise who may have an interest in the issue*<sup>60</sup>.

Involving the local community from the beginning and making them a part of the process gives a sense of ownership and direction to local people. It helps them to become aware of the vision for change and to make a contribution to the transition. After all the use of the term ‘community’ reflects the importance attached to acceptance and assistance from members of the public in their roles as neighbours, friends, shop-keepers and so on, sustaining former residents through supportive relationships that are not solely based on payment.

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<sup>59</sup> ESN Seminar ‘Towards Community Care’, 8-9 May 2009 Warsaw, Presentation by Dieter Kulke, available at <http://www.esn-eu.org/get-document/index.htm?id=264>

<sup>60</sup> *Creating Successful Campaigns for Community Living*, An advocacy manual for disability organisations and service providers, European Coalition for Community Living 2008, available at: <http://www.community-living.info/documents/ECCL-Manual-final-WEB.pdf>

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#### 4. PART II: Conclusions

Ideally, any deinstitutionalisation reform should start with a reflection on how to shape a vision of a future free from large institutions, where people with disabilities and mental health problems, dependent older people and children in care live at home for as long as possible, rather than in a home. Setting out this vision convincingly and transforming it into a plan of action is the role of a leader; s/he needs to create a sense of direction and commitment to change. This cannot be achieved without the participation of users themselves, their relatives, care personnel and the wider community. The transition from institutional to community care is not a transfer from a large to a small care setting, it is a journey to empower vulnerable people to become experts in their own care and to give them instruments that allow them to lead a life they want for themselves.

None of these is however possible without adequate funding. Understanding the (real) cost of institutional care and finding the way to pay for the transition period is not an easy task, but it is not impossible either, as long as there is broad commitment to deinstitutionalisation. Sufficient funding may be found by pooling all budgets, but additional resources could be required for the transition. Wherever the money will eventually come from, it is important that it follows the individual users and not the structures that serve them.

This can only happen if the individual needs of each user are known and the strategic needs of the population are identified and a response is planned. The third part of this report includes chapters on both types of assessments as well as other cross-cutting issues which need to be taken into account in the planning and delivery of local community-based services that aim to empower people using the services.

Notes:

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# Developing Community Care

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Part III:

*Managing  
community care  
services after  
transition*



## PART III

# Managing community care: challenges and opportunities

This part of the report deals with the challenges and opportunities of managing community care and is written with service managers and professionals in mind. It starts with **strategic area needs assessment and planning** – an exercise providing policy-makers with knowledge of the local population and the current capacity of services. On this basis policy decisions can be made and **information and advice** provided to (potential) users and their relatives. When citizens think they may need care and support, they will know where to go for an **independent needs assessment**. This should allow them to make an **informed choice of the service** that best meets their needs and preferences, relying on

policy-makers to ensure service **capacity and availability**. The care and support that users receive should ideally contribute to their overall **social inclusion**. Policy-makers and service providers alike should make sure that services in the community are meeting the **standards** set by the regulator and that the **drive to improving quality** is well-embedded across the whole system.

Following this journey from strategic needs assessment to quality assurance helps in our view to focus on the key challenges that may affect the successful development of local community-based services.

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### 1. Strategic area needs assessment and planning

The vision and leadership displayed in initiating a deinstitutionalisation reform has to continue in order for a community-based service model to perform well. Strategic area needs assessment and planning is one of the elements of a well-functioning community care model. This is a process that identifies the current and projected social and health needs of the local population on the basis of economic, health, employment and sociological data. Ideally, it should also set out the context within which pre-existing services are operating, the main issues they face and a brief assessment of their performance and proposals for improvement to meet service users' needs. A wide range of stakeholders (including user and family groups) needs to be involved in the process to ensure its validity.

In institution-based models, the focus on choice and empowerment permitted by good community care is often missing. In such systems, strategic planning may simply imply increasing or decreasing the number of beds according to waiting lists or projected occupation rates. It may provide limited information about costs and make recommendations about maintenance and renovations needed. Its sole concern is the maintenance of institutional capacity, without questioning whether this is what users and citizens want and need. In community care, strategic planning takes a very broad perspective on the needs of the local population in the medium-term.

In Poland, a nascent form of strategic needs assessment is carried out every year by Regional Centres for Social Policy (RCSP) using Computer-Assisted Web Interviews (CAWI method). The RCSP sends a special questionnaire to the social assistance centres at the municipal and county level and then analyses and compiles their answers in the 'Annual Needs Assessment Report'<sup>61</sup>. This stock-taking helps identify the most urgent needs, plan better for the future allocation of resources and indicate how services could be improved.

Staffordshire County Council's Strategic Plan 2011–2016<sup>62</sup> is a five year strategic plan by which the county is better able to ensure that services likely to be needed can be delivered. Over twelve months, surveys and discussion groups with residents, service users and members of the Staffordshire People's Panel, online consultations, service specific workshops and other events ensured full public engagement. As a result of this extensive consultation, the Council now understands its role differently:

*"Our role is no longer about a set of different services. It is about providing the infrastructure, a range of choices and a culture change to enable people to take control of their lives."*<sup>63</sup>

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<sup>61</sup> 'Bilans potrzeb w zakresie pomocy społecznej' was introduced by the 'Social Assistance Act' of 12th March 2004 and covers all social policy areas such as defined by law and delivered at the local, county and regional level. It is submitted by the Regional Centres for Social Policy to the central government by the 1<sup>st</sup> March every year.

<sup>62</sup> Staffordshire County Council Strategic Plan 2011–2016 *For your family, our community, and a prosperous Staffordshire*, available at: <http://www.staffordshire.gov.uk/yourcouncil/strategicplan/strategicplan2011-2016printfriendlyversion.pdf>

<sup>63</sup> County Councillor Mike Lawrence, Cabinet Member for Children's Wellbeing, quoted in the Staffordshire County Council Strategic Plan 2011–2016, op.cit.

The process of strategic needs assessment should lead to the establishment of a local strategy for service development and improvement. This is the case in Catalonia, where the autonomous government introduced the Programme for Developing Local Plans for Social Inclusion in 2006<sup>64</sup>. These plans establish strategic and operational objectives including how to generate revenue locally and build capacity. They also reflect the new principles to which the government adheres, such as community engagement, promotion of service users' autonomy and the participation of all stakeholders.

Understanding local needs and building local plans around them helps to foster a pro-active attitude among local policy-makers and service providers who can anticipate social trends and be prepared to meet the needs of a changing population now and in the future.

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<sup>64</sup> Read more in: Peer Review: Programme for the Development of Local Plans of Social Inclusion, 7-8 October 2010, Spain Host Country Report, available at: [http://www.peer-review-social-inclusion.eu/peer-reviews/2010/the-programme-for-developing-local-plans-for-social-inclusion-in-catalonia/host\\_country\\_paper\\_es10/download](http://www.peer-review-social-inclusion.eu/peer-reviews/2010/the-programme-for-developing-local-plans-for-social-inclusion-in-catalonia/host_country_paper_es10/download)

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## 2. Information and advice

Information and advice are essential for all users, their relatives and carers who need, or may need, services and support in order to lead their lives. By information, we understand an “open and accessible supply of material deemed to be of interest to a particular population”, while advice covers “guidance and direction on a particular course of action which needs to be undertaken in order to realise a need, access a service or realise individual entitlements”.<sup>65</sup>

One of the primary challenges encountered in closing institutions and developing community care is that users continue to be referred to institutions while awareness of community-based services remains low. This clearly indicates the need to engage not only the public but also those organisations providing information and advice to the public, so that they are persuaded of the values and benefits of community care.

It may at first seem easier for an institution to publicise itself than it is for a community care service. There are constant elements, such as capacity, staffing levels, location and its portfolio of treatments. The building is often a landmark sitting on the same land over many years and is easy to find in a moment of need. Community-based services, on the other hand, tend to be more dispersed and less well embedded in the communal consciousness. They are – or at least should be – more adaptable to users’ needs, again making them more difficult to describe. Service providers which switch from running institutions to running community care services have to change the way they communicate to the public, potential users, funders and organisations providing information and

advice to the public. They have to project confidence, security and commitment to a better quality of life for service users.

Institutions have tended to act as their own gate-keeper, assessing the needs of a user within the framework of care available in the institution. In community care reforms there has been greater emphasis on independent information and advice from public authorities on which service(s) might best help someone. Civil society organisations might also take on the role of independent advisors and advocates on behalf of service users.

Even in systems that have had mainly community-based services for some time, the quality of information and advice can be poor. In a report published in 2008, the Improvement and Development Agency for local government (UK)<sup>66</sup> found:

*“Persistent problems remain including limited information, highly variable responses, poor websites, information written for professional rather than lay audiences; people have specific needs that require more than just an information bank.”<sup>67</sup>*

Similarly in France, a report from the Inspectorate General for Social Affairs (IGAS), says that information is often “*written for professionals and not users*” and available information “*is not presented in a systematic way, thus hindering comparison*”.<sup>68</sup>

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<sup>66</sup> Local Government Improvement and Development (IDEA) website: [www.idea.gov.uk](http://www.idea.gov.uk)

<sup>67</sup> Trafford Council Commissioning Strategy: Information, Advice and Advocacy 2010-2013, available at: <http://myway.trafford.gov.uk/media/70417/info%20strategy%202010.pdf>

<sup>68</sup> IGAS, Rapport sur l'information des usagers sur la qualité des prises en charge des établissements de santé, Inspection générale des affaires sociales (RM2010-090P), published in July 2010, available at : <http://lesrapports.ladocumentationfrancaise.fr/BRP/104000502/0000.pdf>

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<sup>65</sup> Transforming adult social care: access to information, advice and advocacy, report, IDEA, available at: <http://www.idea.gov.uk/idk/aio/9580624>

The internet is increasingly used to provide information and advice about services: in Poland, all the necessary forms (to apply for a benefit) and the contact details of service providers are available on the websites of municipal centres for social assistance. However, given the low level of ICT skills<sup>69</sup> among Polish citizens it is questionable how many potential users can actually access them. The city of Manchester (UK) went further by launching an adult social care website 'My Manchester Services', which brings together all services, providers, addresses and advice relevant to social care. Written in plain English, the website aspires to be an electronic signpost and a resource for users, their carers and family members and professionals.<sup>70</sup> In Flanders, meanwhile, the government decided in 2009 to set up a 'social house' (equivalent of one stop shop) in every municipality. These centres provide information and advice to the local population on all services through their websites, on the phone or face to face.

A single access point, whether virtual or physical, is particularly important when services are fragmented. In countries which opt for a wide array of service providers from different sectors and levels of government, one finds a certain amount of policy and service fragmentation which confuses not only users but also policy-makers.

*"This of course does not invalidate the multi-actor and partnership approach; it simply highlights the need for close cooperation and the coordination of services, such as the 'open stop shop', a central access point for a range of services and providers which offers information for users."*<sup>71</sup>

The development of community care has to go hand in hand with efforts to provide independent information and advice about needs assessment, entitlement to certain benefits and available services in the local area. Any guidebooks or communications need to be written in plain language with service users in mind, free of legal or technical jargon and available from different sources and in various media.

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<sup>69</sup> According to Eurostat test designed to establish people's IT literacy; read more at: <http://epp.eurostat.ec.europa.eu/tgm/mapToolClosed.do?tab=map&init=1&plugin=1&language=en&pcode=tsdsc460&toolbox=types>  
<sup>70</sup> My Manchester Services website: [www.manchester.gov.uk/mymanchesterservices](http://www.manchester.gov.uk/mymanchesterservices)

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<sup>71</sup> ESN Report Access to Quality Social Services, published in 2005, available at: <http://esn-eu.org/get-document/index.htm?id=169>

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### 3. Individual needs assessment

Being aware of the existing services in the community and knowing where to find out more about them helps in the moment of need, when someone's life circumstances change and the need for support arises. Whatever the reason of this situation, anyone should be entitled to an independent needs assessment. This usually involves a specialist (or a multidisciplinary team) working with the service user (and their family) to identify their needs and how they might best be met. Service(s) involved in the assessment should then prepare a care plan, covering<sup>72</sup>:

- when and how often the user will get support
- the organisations which will provide the support
- contingency plans to cope with emergencies
- any care and support provided directly by a person's family or friends
- a date when the services plan to review the needs and support arrangements
- an assessment of the user's income and assets to work out their share of the cost.

Such an approach is a prerequisite for personalised care and prevents 'one-size-fits-all' solutions and the routine treatment typical of institutional culture.

In institutions, needs assessment tends to be carried out by the staff of the institution, which assesses a person's needs in the context of what the institution can offer. In good community care services, it means a complete assessment of a person's needs and life circumstance and leads to the delivery of a variety of services perhaps from different providers. Unfortunately, this is often

restricted to classifying a person according to different levels of disability or dependency and allocating a budget or a service level accordingly. In Slovenia, for example, older people with care needs are divided into four categories: 1) mobile users; 2) partially mobile; 3) immobile and 4) totally dependent. The decision is made by a local GP and is subject to review and control by the national insurance system<sup>73</sup>. An assessment of a person's income and assets (means-test) is often part of the same process and is designed to evaluate how much they can contribute to the cost of their care.

Joint assessment by health and social services is becoming more and more established in long-term care for older people and within mental health care, although in some countries, the inheritance of a medicalised care model may be a barrier to good practice. In Romania for instance, the assessment system for disabled people uses classification and labelling, based on a medical typology of diseases, to establish the degree of disability. A NGO activist from Transylvania explains how this outdated approach works:

*"A child may be diagnosed as 'autistic' but the day (s)he turns 18, (s)he becomes 'psychotic'. This label does not say anything about the real needs of the person and gives no orientation to a specific service."*<sup>74</sup>

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<sup>72</sup> Based on *Directgov – public services all in one place* website, section on disability and support mechanisms, available at: [http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/ArrangingHealthAndSocialCare/DG\\_4000436](http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/ArrangingHealthAndSocialCare/DG_4000436)

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<sup>73</sup> CEPS ENEPRI Research Report No. 87, Long-term care system in Slovenia, June 2010; available at: <http://www.isn.ethz.ch/isn/Digital-Library/Publications/Detail/?id=122421&lng=en>

<sup>74</sup> Peer Review Combining choice, quality and equity in social services, Denmark 01.04.2009; Romania independent comment paper <http://www.peer-review-social-inclusion.eu/peer-reviews/2009/combining-choice-quality-and-equity-in-social-services/romania-dk09/download>

A related problem is the dominance of the medical over social professions and their higher public profile. It is vital that needs assessment in community care is about the whole person not only about their condition or disability.

In the past, needs assessment tended to be restricted to users' areas of vulnerability such as their disability, age or illness; now it includes users' dreams and aspirations, their relations with loved ones, and their education and employment opportunities. Professionals – often working together in a team – can think with the user about how community services could support them to fulfil their potential.

The results of these conversations should be gathered in a clear personal document owned by the service user, produced by the user with professional support. In the London Borough

of Redbridge for instance, personal dossiers for people with a learning disability are in some cases full of photos and drawings which express their needs, wishes and dreams.

Finally, needs assessment should be reviewed periodically as most people's health and wellbeing change over time. Any changes identified should be reflected in an updated care plan. This is particularly important for users leaving an institutional setting to start living in the community, who may gain confidence, develop new skills and see their health improve. Alternatively, where a person's health and condition deteriorates in either setting, they may need more assistance. As an individual's needs change, so the services should adapt, which may in turn imply a change in the cost of care.

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#### 4. Service capacity and availability

In a good community care system, the initial provision of information and advice would be followed by needs assessment and means-testing, after which the next step would be for a person to start using services. Service capacity is simply about whether there is enough supply to meet the demand for services, whilst availability is about ensuring that people in all regions are able to use community care services. This is where issues of geographical coverage and capacity may arise – if they have not already arisen when the person first seeks advice.

The simplest indicator of low service capacity is perhaps a waiting list, the existence of which may reflect a failure of strategic planning or adequate funding. This phenomenon touches both community care and institutions and can be interpreted in different ways. Directors and trustees of institutions may interpret such lists as a vote of confidence and the expression of a genuine wish to live there. However, it is more likely that they point to a lack of alternatives and that local people, faced with an uncertain future, choose what they know best – the institution. Waiting lists can be a self-perpetuating vicious circle, once the local population becomes aware of them; people apply for needs assessment or services earlier than necessary, in order to secure a place in the future. In community care, a waiting list may similarly be seen as a signal of a growing confidence in a new model following deinstitutionalisation; it is still, however, also a reflection of poor planning and inadequate funding.

Even in countries where community care has been long-established, geographical coverage is still likely to vary between rural and urban areas. In many places, this divide is compounded by the poor economic performance of some underdeveloped, mainly agricultural, regions. Remote rural areas from Finland to Spain to Serbia are not sufficiently well-covered in terms of services and the migration of young people to cities further exacerbates this problem.

*“Universal public service provision has at times failed to reach people in need and has grown more and more expensive, small NGOs and private companies of one or two local people who are also partly supported by the State have started to provide services such as meals on wheels, gardening, cleaning, hygiene and escort services for a small fee”<sup>75</sup>.*

Hungary had established community-based services for people with mental health problems, but their coverage is rather ‘symbolic’ according to an ESN member. In a country where some 300 000–400 000 people face severe mental health problems at least once in their life and need help to recover, we find no more than “50 day-care mental health centres and about 90 mobile case management teams, altogether reaching between 5000 and 7000 users.” A similar problem is observed in Romania where the total number of people with intellectual disabilities is around 89 000 and according to official statistics ‘only 96 persons live in a group home, equalling 0.11%. In addition, only 263 persons have a place in a day care centre (0.3%)’<sup>76</sup>.

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<sup>75</sup> ESN Report Access to Quality Social Services, op.cit..

<sup>76</sup> Peer Review, Denmark 2009; Romania independent comment paper, op.cit.



The availability of even the most basic services was very limited in rural areas of Hungary, long after the fall of Communism. In response to this service gap, Hungary started developing a local service model centred around a village-based 'Gondnok' or 'caretaker' in 828 villages and settlements. The programme proved so successful that it has been further developed and is now recognised as a key feature of the system. Caretakers perform a whole range of services including driving people to day care centres, picking up their medicine, collecting children on their way to and from school, preparing and distributing 'meals on wheels', etc. These basic services enhance a person's independence and allow them to stay in their own homes for longer.<sup>77</sup>

The capacity and availability of services should be maintained by local authorities on the basis of strategic needs assessments, local planning and budgetary responsibility. Demographic trends, migration, technological advancement and the economic situation can significantly impact on capacity and availability, as can the changing needs and preferences of service users.

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<sup>77</sup> Read more in the ESN synthesis report on 'Basic Social Services in Rural Settlements, Village and Remote Homestead Community Care-Giving in Hungary' available at: <http://esn-eu.org/get-document/index.htm?id=141>

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## 5. Choice

In community care, choice is a broad concept: it is not only about a choice between different providers of the same service or between different services altogether, but also about how a person lives their life. We saw earlier in this report how human rights instruments support the idea of choice, since they allow a person to take control of their life, i.e. to be independent and free. When a person exercises choice, it should be an informed choice about what services they will use, where they will live and what they will do with their life in terms of education or work. This leads us back to the importance of clear information and advice and a clear assessment of a person's individual needs and preferences. This may entail the acceptance of some risks (e.g. the risk that they face stigma in the community or that the job they get doesn't work out) in return for the opportunity of a better quality of life.

Meanwhile, in an institution, choice may be thought of as a choice of special facilities within its walls. Indeed, there is a widespread belief that only larger institutions are able to guarantee facilities such as a swimming pool or the daily presence of a specialist doctor. The view that institutions offer more choice – arising from a misunderstanding of what sort of choice is meant – was dismissed in the European report of 2009 which points out that institutions tend to treat all the residents in the same way, restricting individual choice in favour of developing routines.

Giving choice to service users is not an easy task and many countries struggle to make it happen. In Estonia the entry of new long-term care providers into the market is slow because of low profit margins, so choice of services is simply not possible because of

limited supply.<sup>78</sup> Typical measures to enhance choice in community care include personal budgets or vouchers, which can stimulate the market, but there may be opposition on the grounds of “*additional administrative burdens and monitoring problems.*”<sup>79</sup> In countries with low service capacity, providers may be able to choose to whom they offer a service, potentially ‘creaming off’ the least problematic and least costly cases. This is the very opposite of the sort of choice which we wish to advocate.

Some countries experience wide regional differences when it comes to opportunities to make an informed choice between providers. ESN members report that choice is possible in northern and central Italy, where social services have good geographical coverage due to better funding and staffing across the public, for-profit and non-profit sectors. In southern Italy however, choice is unlikely to be possible because of basic services either do not exist at all or have insufficient capacity; the South relies extensively on informal family care, supplemented by the employment of migrant carers, compensating gaps in formal services.

In Central and Eastern Europe community-based services are still regarded as untested and more likely to be closed down prematurely (i.e. when the funding is withdrawn by an external donor or when the government changes). It is not surprising therefore that vulnerable people and their relatives favour an institution over care in the

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<sup>78</sup> Peer Review: Combining choice, quality and equity in social services, Denmark 01 April 2009; Estonia paper, available at: <http://www.peer-review-social-inclusion.eu/peer-reviews/2009/combining-choice-quality-and-equity-in-social-services/estonia-dk09/download>

<sup>79</sup> Peer Review: Combining choice, quality and equity in social services, Denmark 01 April 2009; Hungary paper, available at: <http://www.peer-review-social-inclusion.eu/peer-reviews/2009/combining-choice-quality-and-equity-in-social-services/hungary-dk09/download>

community. Although legislation may clearly support community over institutional care, the reality on the ground makes it difficult to access these services, so people tend to apply for residential care, as noted by a Czech ESN member:

*“In many cases, demand surpasses supply to such an extent that even talking about choice is disingenuous. People go for residential care because it is there, even if the waiting lists are getting longer and longer.”*

Finally, the ability to choose may be restricted by financial considerations, as community care is often subject to co-funding by users. More affluent people would be able to purchase services of better quality. This is the case for instance in Lithuania where the price of social care services is not regulated and providers are able to set their own fees. The more expensive services tend to offer better quality but in practice the least expensive service may be favoured because it is affordable to people in need.<sup>80</sup>

Special legislation may sometimes be required to make choice a reality for service users. In Sweden, the government passed the ‘Freedom of Choice’ Act in 2009 introducing vouchers that entail the same payment per hour, regardless of the provider. In this model, the pool of available providers is based on certification by the municipality, which can set various quality criteria. Competition between providers for service users is expected to drive up the quality of care and further stimulate the market.<sup>81</sup>

Likewise, personal budgets can further stimulate the market, helping the best providers to expand. If well-managed, they transform users from passive recipients of care into co-producers. However, this requires a clear legislative framework, protecting users and providers, a stable financial mechanism and clarity as to what should be available to all persons in need free of charge and which services are means-tested and co-funded by users.

The introduction of personal budgets can sometimes produce unexpected results. When they were rolled out in Sweden, people with disabilities organised themselves to pool their resources and purchase their care collectively, effectively becoming the administrators of their own care.

In the Czech Republic, personal budgets, introduced in 2007, have failed to produce desired outcomes in terms of improved services on offer and better choice for users. The lack of control mechanisms and insufficient flexibility of service providers have led a large number of people to keep their budgets as a supplement to their income rather than as a means to purchase care.

According to ESN’s observations, personal budgets can be a powerful tool, helping to focus funds and efforts on people rather than structures, but they will not miraculously create choice in community care. They can stimulate the supply side when the market conditions have been created and social care providers are ready to compete fairly for custom. However, the market still needs careful management to ensure a decent level of quality for all.

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<sup>80</sup> Peer Review Combining choice, quality and equity in social services, Denmark 01.04.2009; Lithuania paper <http://www.peer-review-social-inclusion.eu/peer-reviews/2009/combining-choice-quality-and-equity-in-social-services/lithuania-dk09/download>

<sup>81</sup> ESN Report Contracting for Quality, published in 2010, available at: <http://www.esn-eu.org/get-document/index.htm?id=498>

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## 6. Quality assurance, inspection and improvement

The transition from institutional to community care should have as a goal the improvement of service users' quality of life, i.e. their total well-being, including all emotional, social, and physical aspects of the individual's life. It is important to recall that the transition is not a process of moving users from low-quality residential care to equally low-quality community care. Unless a high quality is assured, community care can also result in a poor quality of life for service users and social exclusion. How to ensure and continuously improve quality of care and quality of life for people using (community-based) social services is one of the most challenging questions.

Quality of life (the well-being of an individual) is often confused with quality of service, which indicates a provider's respect for government regulation. In institutional care, the second type of quality is easier to observe. Institutions can follow the parameters set by the regulator, such as the ratio of staff to residents or the space per person in a room. Where they score worst is in the quality of life area, as their set routines, size and institutional culture tend do not favour individual preferences. In community-based services, it is arguably more difficult to measure quality of care, as services are more flexible, responding more readily to users' needs. This however makes them more likely to see an individual as a whole person with emotional, social and physical needs.

An interest in quality (of care) has led to the development of quality standards and benchmarks against which it can be measured. In Central and Eastern Europe – unlike in the 'Old Member States' – the first quality standards were introduced to improve

public sector services. Publicly-run centres and homes have had to comply with a number of rules regarding staffing, room size, opening hours and case management. This has by and large not yet been extended to for-profit and non-profit providers as they were not present on the market or their activity had not been registered as 'social'.

In Poland, for instance, privately-owned long-term care institutions have often been registered as 'hotels' or 'recreational farms' to avoid registration and inspection. The residents may have benefitted from lower fees and shorter delay in access, but often at the cost of proper social and health care, extending to neglect and abuse reported in the Polish media. This problem has now been recognised by the Ministry of Labour and Social Policy and there is discussion going on as to how to raise awareness of the risks associated with unregistered care homes and how to encourage providers to enter the social care system.

Quality standards across Europe are very varied. Indeed, in some countries they vary significantly from one region or municipality to another. This has led a number of countries to start looking into general quality assurance systems, either applicable to a given type of service (e.g. child care) or extended to all social services. This would often involve the registration of service providers, regular reports by providers against nationally agreed standards and the inspection of service facilities.

A number of systems have been also developed at the European level: EQUASS<sup>82</sup>, E-Qalin<sup>83</sup> and the recent *Voluntary European Quality Framework for Social Services*<sup>84</sup> developed by the Social Protection Committee.<sup>85</sup> The SPC framework “*aims to develop a common understanding on the quality of social services within the EU by identifying quality principles that these services should fulfil.*” It is designed to be “*flexible enough to be applied in the national, regional and local context ... and to a variety of social services*” and to be “*compatible and complementary with existing national quality approaches.*”

The European Quality Framework sets out four categories of quality principles:

- general principles for service provision (e.g. availability, affordability, comprehensiveness, person-centred approach)
- principles for the relationships between service providers and users (e.g. participation, empowerment and respect for users)
- principles for the relationships between service providers, public authorities, social partners and other stakeholders (e.g. partnership and good governance)
- principles for human and physical capital (good working conditions, adequate infrastructure).

While recognising the structural and procedural dimensions of quality care (buildings, staffing, process, outcomes) it also takes into account the user’s perspective in terms of respect, dignity and empowerment.

These values, attributing to the quality of life of vulnerable people are often absent from regional or national quality systems, given how difficult it is to measure them, especially when compared to numerical parameters such as surface, staff ratio etc. In Bulgaria, for example, according to an ESN member, “*monitoring of quality is focused mainly on the appropriateness of spending and not in terms of impact on quality of life.*”

Service providers should ideally have their own quality management system in-house – EQUASS and E-Qalin are examples. This is a good demonstration of their commitment to quality care and to continuous improvement. In ESN’s recent ‘Contracting for Quality’ study<sup>86</sup>, providers of care for older people in Spain, Sweden and the Czech Republic reported using ISO or EFQM-based systems or had developed their own. For these providers, the commitment of the funder (mostly local or regional government) to quality was also important in choosing where to operate. Some local authorities would be very supportive of quality improvement; Surrey County Council (UK), for example, provides grants to providers which have performed poorly in national inspections.

The role of external (independent) inspection is also key to assuring that standards (whatever their scope) are respected. Recognising this, the Czech Republic launched a pilot project to establish standards and inspection in social care sector in 2000. Six years later, an independent inspection agency with 14 regional branches has been set up.<sup>87</sup> In Scotland, the Social Work

<sup>82</sup> European Quality in Social Services (EQUASS), information available at: <http://www.epr.eu/index.php/equass>

<sup>83</sup> Quality management in the care for the elderly: E-Qalin, information available at: <http://www.ede-eu.org/index.php?page=eqalin>

<sup>84</sup> Voluntary European Quality Framework for Social Services (SPC/2010/10/8 final) available at: <http://ec.europa.eu/social/BlobServlet?docId=6140&langId=en>

<sup>85</sup> <http://ec.europa.eu/social/main.jsp?catId=758&langId=en>

<sup>86</sup> Leichsenring K., Barnett S., Rodrigues R. (2010). *Contracting for Quality*, European Social Network. Available at: <http://www.esn-eu.org/get-document/index.htm?id=498>

<sup>87</sup> ESSC, 22-24 June 2009 Prague, Workshop presentation by the Czech Ministry of Labour and Social Affairs, Central Bohemia Region and Bellevue (service provider) available at: [http://www.esn-eu.org/prague/downloads/workshop\\_presentations/3\\_MoLSA\\_Cermakova\\_fin.ppt](http://www.esn-eu.org/prague/downloads/workshop_presentations/3_MoLSA_Cermakova_fin.ppt)

Inspection Agency<sup>88</sup> inspected all social work services in Scotland until April 2011 and reported publicly and to Parliament. SWIA placed great emphasis on getting first-hand evidence about the quality of services in a given municipality:

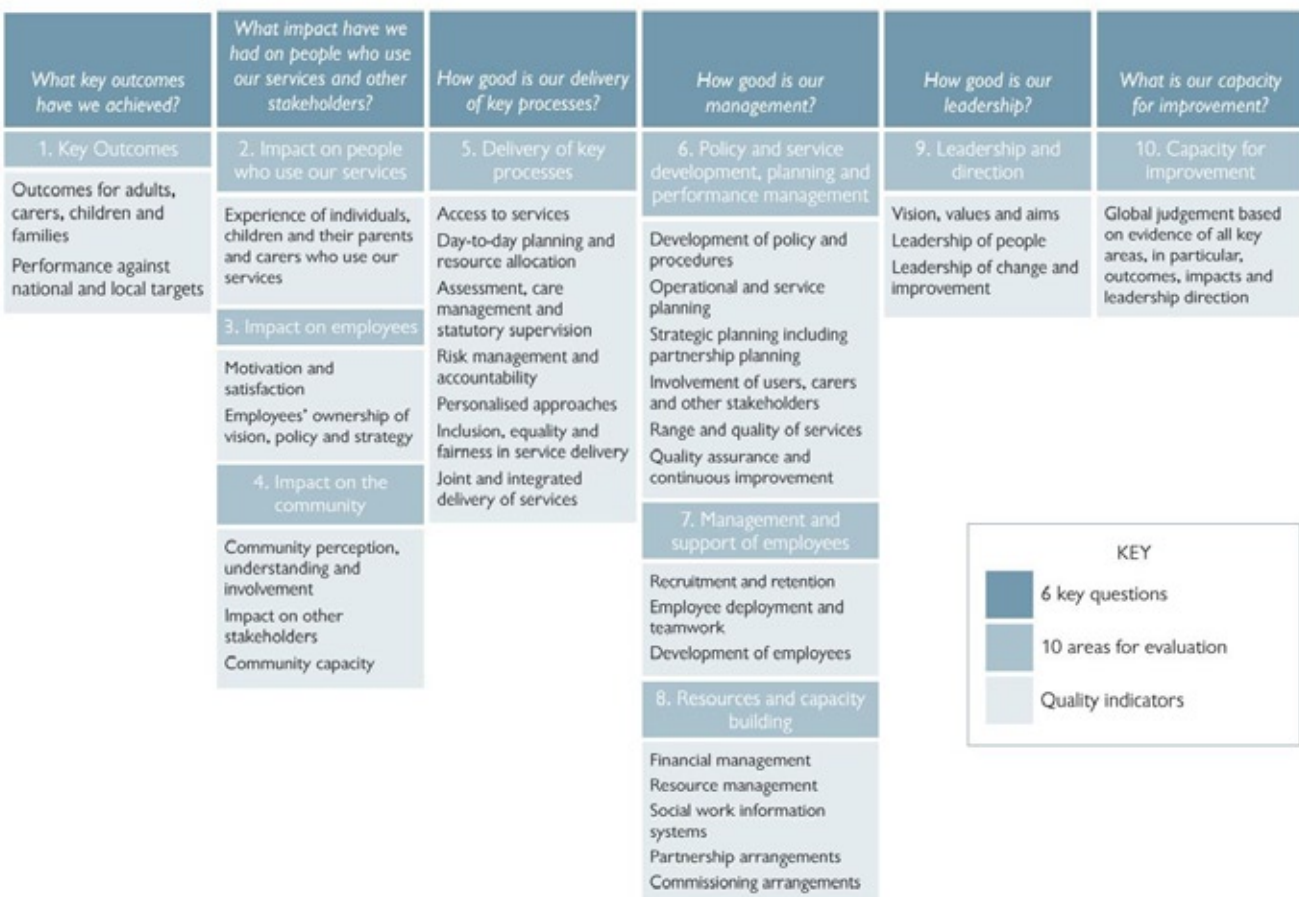
*“Our independent systematic scrutiny of services [was] based on grassroots evidence from people who use services: carers, staff and other key stakeholders.”*

While registration and inspection of providers was carried out by a different agency, SWIA’s inspection model (see diagram below) took a broad view of the whole system in a given area from information and advice to service users to strategic leadership by the local authority.

In the transition from institutional to community care, it will take time to move from a system of inspecting institutions (if one was in place) against structural standards to one which is capable of assessing outcomes for service users in terms of quality of life and to supporting all actors in the community care system to continuously improve their service to people. This requires a commitment to change, inspired by a vision and an efficient leader that will help the inspection services to break away from the static ‘compliance with the rules’ model to the more dynamic, results-oriented model which promotes a culture of self-improvement and firmly puts people and not structures at the heart of all interactions.



### PERFORMANCE IMPROVEMENT MODEL (PIM)



<sup>88</sup> On 1 April 2011 the work of the Social Work Inspection Agency passed to a new body, Social Care and Social Work Improvement Scotland (SCSWIS). The PIM is available at: <http://www.scotland.gov.uk/Publications/2009/01/14115818/4>

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## 7. Social Inclusion

The transition to and development of community care should be pursued vigorously in light of the human rights to respect, choice, participation and protection, social work ethics of empowerment and individual strengths, and the testimony of former residents of traditional institutions. Being cared for in an institution, whether as a child, as a disabled person or an older person, means being away from home, often in a different town or region altogether and having limited contact with the world outside, including with family and friends. It sets people apart, segregates and labels them; it does not give people a life like others and with others: it is a mass form of social exclusion.

Community care, on the other hand, aims to keep people in the local community at home or in a home-like environment for as long as possible, giving them the best chance of achieving full social inclusion. Good community-based services focus on improving or maintaining users' independence to let them – as far as possible – live their lives the way they want. Sometimes, providers offer services to users and the public, thus breaking down the barrier between 'people in need' and 'normal people' who may just happen to like the local meditation course or community café. Some community-based services are located next to the local library, doctors' surgery or other public services. They create opportunities for users of services to interact in 'normal' circumstances with neighbours, friends and relatives.

It is nonetheless important to note that the development of community care does not automatically lead to full social inclusion; it merely creates the conditions for it. Living at home can lead to social isolation, e.g. for an older person with reduced mobility, whose family have moved away to other parts of the country; apart from their care workers, they may not see anyone else. An ESN member in Iceland reported that some older people have even preferred to move to small-scale sheltered accommodation units because they feel more secure there and more easily have contact with others.

In Italy, where the process of deinstitutionalisation began in the late 1970s, much remains to be done to foster neighbourly relations between people using social services and the rest of the community. An ESN colleague from Italy notes:

*“Expectations were not met: many service users remain without work, have limited social contact and often live in sheltered environments.”*

The transition to community care is often a traumatic experience for users who may have been isolated from society for many years. It is not an easy journey to develop or regain social skills and have the courage to enter into contact with strangers. The local population may also make it difficult for former residents of institutions, shying away from them, ignoring them or even resorting to verbal and physical violence. Both Italian and US experiences show that both sides – former residents and local people – need help to prepare for the transition to services in the community.

The attitudes of the general population towards former residents can contribute to the success or failure of deinstitutionalisation. In Sweden, a lot of attention was paid to this issue and some remarkable progress has been made<sup>89</sup>:

*“We have gone from large institutions to single or group homes and integration into society. In the past people with disabilities were hidden away – today they can even be seen in commercials and on reality TV.”*

Yet, the Swedish ESN members recognise how important it is to raise awareness about disabilities and mental health problems. Some people, especially those with mental health issues are still stigmatised:

*“Leaders have to lead by example and make sure that we treat the mentally ill as equal citizens, we respect them and assist them discreetly to live a life ‘like others and with others’.”*

These negative stereotypes and prejudices take a long time to die out. People leaving institutions are often faced with an unwelcoming local population, concerned for their safety and the reputation of their neighbourhood. In the Czech Republic, social workers and managers spent a lot of time going door to door, talking to neighbours about the plans to set up supported flats in their area. Initially, their response was negative, but soon after the first people moved in, their attitude changed from hostile to indifferent. Although this is a positive development, there is still a long way to go before these users will be integrated in the community.

Finally, in order to strengthen social cohesion and inclusion, services in the community must be coordinated and interconnected to meet both basic and complex needs. This is often not the case. An Italian ESN member argues that the Italian deinstitutionalisation reform of 1978 did not live up to its expectations because the newly established community mental health services were disconnected from social and employment services. In smaller municipalities, where everyone knows everyone, this has been mitigated through personal contacts between relevant service personnel. However, in bigger cities, there are greater risks of social exclusion of mental health service users.

Unlike institutional care, community-based services have the potential to contribute to social inclusion. This will not happen without a skilful local leadership and its ability to make it ‘everyone’s business’ to prevent institutionalisation and to create conditions for even the most vulnerable members of the community to be included and lead as normal a life as possible. The extent to which former residents of institutions participate in education and employment, the level of stigma among the population, will be major indicators of the success of deinstitutionalisation in moving from a situation of social exclusion to one of social inclusion.

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<sup>89</sup> Quote from an ESN member



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## Part III: Conclusions

Setting up and developing effective local community care is a challenging task. Ideally, it should begin with a strategic area needs assessment and planning which identifies the current and projected needs of the population. On the basis of this aggregate information, local policy-makers can make informed choices about funding, design and delivery of local care.

A similar individual assessment must also be performed for every person requiring care or support to identify their needs and preferences, and to put services in place accordingly. Each user should also have access to information and advice services to learn about their entitlements and responsibilities, local providers and their services in order to weigh-up their options.

Once an individual's needs assessment is completed and the user is aware of his/her options, (s)he should be able to access services of his/her choice. To make this possible, local policy-makers need to ensure that services are available, varied and sustainable. There may be structural obstacles to remove first and the capacity and

availability of a range of services may need to be improved over a period of time.

Any new or pre-existing community care services should have as a goal the improvement of service users' quality of life, i.e. their total well-being, including all emotional, social, and physical aspects of a person's life. This means moving from a system of inspecting services against structural standards to one which is capable of assessing outcomes for service users in terms of quality of life and to supporting all actors in the community care system to continuously improve their service to people.

Finally, local leaders need to remain vigilant not to recreate a rigid institutional culture in community care, thus perpetuating the circle of stigma and social exclusion. Unlike institutional care, community-based services have the potential to contribute to social inclusion, but this will not happen automatically. There needs to be good leadership in order for it to be 'everyone's business' to create the conditions for even the most vulnerable members of the community to be included and lead as normal a life as possible.

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## NEXT STEPS

Launching deinstitutionalisation reforms means changing the focus from structures and procedures to people. It is about listening and respecting their wishes, promoting their autonomy and preserving their dignity. Replacing the institutional care approach with community-based services is considered by some “the most important change in policy and pattern of service provision (...) in the last 50 years.”<sup>90</sup>

The message of this report is that a transition from institutional to community-based care is desirable and – despite difficulties – achievable. It is an opportunity to build more cohesive and dynamic local communities where everyone’s potential can be realised. Communities, which foster talent and remove barriers stand a better chance of thriving economically and of being seen as a good place to live and do business.

We can all play our part in this process. Universities and research institutes across Europe can contribute to a better understanding of the phenomenon of institutionalisation by developing a common terminology and assessing strengths and weaknesses of both community and institutional care. They can also help in improving our knowledge of the cost-effectiveness of social policy intervention. This kind of research, led by Prof. Martin Knapp in the field of mental health, provides scientific answers to the question ‘what works’ and demonstrates where it is the most profitable to invest ever more scarce public resources. Furthermore, scientists can propose a common methodology to collect better data. This would help statistical offices in the EU27

to gather and assess local and regional data on both institutional and community care capacity and sustainability, ideally using the same European indicators. Standardised and comparable statistics would open the way to European benchmarking and could inform the debate about the future reforms and development in the social policy field.

The European Commission can itself give a strong incentive to further develop community care alternatives. Indeed, the Commission is already involved in the process and “funds studies on the delivery of community-based services (...) to attain the right levels of security, freedom and independence for community living”<sup>91</sup>. DG EMPL, REGIO, SANCO and JUST are involved in the meetings of the European Expert Group on Transition to Community Care and support its mandate. Nonetheless, there is still a question of EU structural funds being used to repair or refurbish large outdated institutions in the New Member States which needs to be addressed. This can be done within the framework of Europe 2020 Strategy, as indicated in the Communication ‘European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe’, where the Commission commits itself to action:

*“Promote the transition from institutional to community-based care by using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people”.*<sup>92</sup>

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<sup>90</sup> Mansell J., Ericsson K. (eds), *Deinstitutionalisation and Community Living: Intellectual Disability Services on Britain, Scandinavia and the USA*, London: Chapman and Hall 1996

<sup>91</sup> DG JUSTICE, Tackling discrimination – People with Disabilities front page, available at: [http://ec.europa.eu/justice/discrimination/disabilities/index\\_en.htm](http://ec.europa.eu/justice/discrimination/disabilities/index_en.htm)

<sup>92</sup> Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions ‘European

This important commitment has also been reflected in the draft regulations concerning EU Structural Funds for the period 2014–2020, which both mention the ‘transition from institutional to community-based care’ one of the eligible actions under equal opportunities and combating poverty and social exclusion headings.<sup>93</sup>

Member States also have an important role to play. They are ultimately responsible and accountable to their citizens for the shape and quality of social policy and practice. They are in the position to introduce and lead on the legislative changes that can favour community care development. They can ring-fence funds necessary for building up local capacity and protecting community-based services in the first years, while gradually phasing out support to large institutions.

Finally, ESN and its members also have a role to fulfil. We can complement the Commission’s policies and funding mechanisms through small scale, practical support for people in leadership roles at different levels to enhance their capacity to lead the transformation of social

services that promote choice and independent living in the community. ESN training programme ‘Managing Change: the role of public authorities in deinstitutionalisation’<sup>94</sup> was designed with the co-author of the DECLOC report and brings together public sector professionals and politicians from four Central and Eastern European countries. These individuals will become a nucleus for change in their municipalities and regions.

ESN members can also share their own stories in moving from institutional to community care and support colleagues who are yet to embark on this journey. There is a wealth of experience among us and we need to make our voice heard.

Now is the time to make it our priority to end the segregation and social exclusion of vulnerable people. It should be our shared aspiration to provide these people with the same choices and control over their life that we all enjoy and to support them to live as normal a life as possible in their communities.

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<sup>93</sup> Proposal for a Regulation of the European Parliament and of the Council on the European Social Fund and repealing Regulation (EC) No 1081/2006 available at: <http://ec.europa.eu/esf/BlobServlet?docId=231&langId=en> and Proposal for a Regulation of the European Parliament and of the Council on specific provisions concerning the European Regional Development Fund and the Investment for growth and jobs goal and repealing Regulation (EC) No 1080/2006 available at: [http://ec.europa.eu/regional\\_policy/sources/docoffic/official/regulation/pdf/2014/proposals/regulation/erdf/erdf\\_proposal\\_en.pdf](http://ec.europa.eu/regional_policy/sources/docoffic/official/regulation/pdf/2014/proposals/regulation/erdf/erdf_proposal_en.pdf)

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<sup>94</sup> <http://www.esn-eu.org/e-news-dec11-managing-change-training-programme/index.htm>

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Notes:

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## READING GUIDE

The authors hope that you will be able to easily navigate through this study using the Introduction and the table of contents.

Although we hope you will read the whole report, if you are interested in any of the following, here are some suggestions about what to look for:

- *Not sure what deinstitutionalisation really means*, i.e. how to understand the terms used in this reports, please read the glossary
- *Wondering why community care is a better than institutions*, i.e. what are the key arguments supporting the transition from institutional to community-based care, please read Part I
- *Thinking of transition to community care and not sure where to start*, please read Part II which describes key elements you need to have in place
- *Facing challenges in managing community care following transition*, please read Part III which outlines elements of a well-functioning community care model drawing on various practice examples.

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## HOW CAN I USE THIS REPORT?

This report is clearly intended to be informative, but also thought-provoking. You may want to reflect further on your country, region or municipality's role in the process of deinstitutionalisation and community care development, by asking yourself any or all of the following questions:

- What kind of community-based care is available where you live?
- What kind of arguments would be most effective in convincing local policy-makers and colleagues in other services of the need for deinstitutionalisation?
- What are the drivers and the obstacles for you locally in making the transition to community-based care a reality?
- Is it really so expensive to close institutions? What is the long-term return on investment of community care?
- How can local resources be mobilised to provide better care for vulnerable people?
- What kind of partnerships and alliances are needed to bring about this change?
- How can you win round staff, residents and local people to the benefits of community-based care and make social inclusion everyone's business?

This report is available in English, Hungarian, Czech, Romanian and Polish. We will also be able to put you in touch with members of our High-Level Advisory Committee, Policy & Practice Group and participants in the training programme, who can share their expertise and experience of developing community care, from a number of countries and in a wide range of languages.

For several years, the European Social Network (ESN) has been working with service managers and policy experts in its policy and practice group and high level advisory committee on the issue of transition from institutional to community-based care. The report 'Developing Community Care' outlines the case for deinstitutionalisation, the first steps in the transformation of services and the key elements for good quality community care.

ESN is also offering strategic support to policy-makers and service managers from the Czech Republic, Hungary, Poland and Slovakia in a training programme that is running during 2011-12. Meanwhile at EU level, ESN is a Member of the European Expert Group on Transition from Institutional to Community Care, which raises awareness of the issue in EU policymaking and funding programmes.

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