Deinstitutionalisation and community living – outcomes and costs:

report of a European Study

Volume 2: Main Report

Jim Mansell, Martin Knapp,
Julie Beadle-Brown and Jeni Beecham

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1. Introduction

This project aimed to bring together the available information on the number of disabled people living in residential institutions in 28 European countries, and to identify successful strategies for replacing institutions with community-based services, paying particular attention to economic issues in the transition. It is the largest study of its kind ever undertaken.

Background

In Europe, residential institutions have been the typical response to the needs of disabled people needing accommodation and assistance with daily living since the early 19th Century. Often established to relieve suffering and with humane ideals, institutional care gradually became an instrument of segregation and control, in which poor standards of care became accepted. Following the Second World War, some countries began to move away from large residential institutions. Governments in these countries began to develop policies for the shift from institutional care to the provision of care and support in local communities. This was prompted by different factors in different countries. Changing ideology and the rise of normalisation, the occurrence of scandals in institutions and the rise of lobbying organisations have each played important roles in different countries, with the respective influence of the three factors varying between countries. Three movements in particular have been influential in this process:

- The *Independent Living Movement* began among people with physical impairments and has focused on providing personal assistance and adapted environments to enable people to live like anyone else in the community.
- The *Anti-Psychiatry Movement* began in mental health services. It has focused on empowering service users and survivors to live in society and on the adoption of a social model of mental health rather than a medical model.
- *Deinstitutionalisation and community living* has been particularly important in services for people with intellectual disabilities and it has also been influential in mental health services. It has focused on the orderly abandonment of large institutions and their replacement by personal assistance and accommodation in the community.

From the 1960s onwards, the movement towards deinstitutionalisation has become much stronger. Although initially confined to those with less severe disabilities, in more recent years it has expanded to include people with the most complex disabilities.

The goal for Europe

These different traditions have converged as practical experience of good practice has developed. Increasingly the goal of services for people with disabilities is seen not as the provision of a particular type of building or programme, but as the provision of a flexible range of help and resources which can be assembled and adjusted as needed to enable all people with disabilities to live their lives in the way that they want but with the support and protection that they need. The most recent iteration of this approach is characterised by several features:

Separation of buildings and support
The organisation of support and assistance for people is not determined by the type of building they live in, but rather by the needs of the individual and what they need to live where and how they choose. High levels of support can be provided in ordinary housing in the community, for example. This approach involves treating the person as an individual and providing sufficient support to meet their needs and promote a good quality of life, not trying to fit the person to the already existing services.

Access to the same options as everyone else
Instead of, for example, determining that all disabled people must live in group homes, policy is framed around people having access to the same range of options as everyone else with regard to where they live and receiving the support they need wherever they may choose. This principle is closely allied to the principle of *universal design*, by which facilities available to the general public are designed so as not to disadvantage disabled people.

Choice and control for the disabled person and their representatives
Help is organised on the principle that the disabled person should have as much control as possible over the kind of services they receive, how they are organised and delivered, to fit in with the person's own aspirations and preferences. Where people are not able to exercise control over all aspects of their life, arrangements are made for others who care for them to protect their interests and help make decisions which promote the individual's quality of life.

The above approach to support is sometimes referred to as “supported living”, entailing the separation of support from the provision of accommodation. People own or rent their own home and support is provided to them within their own home or provided to facilitate access to employment, education, leisure or other activities in the community. When support is more of the form of outreach from a community based team, visiting the person regularly to provide assistance with particular tasks or access to particular activities, then this is often referred to as ‘independent living’. Where people are involved in planning their support, such as where they live and who supports them and can therefore can also decide on how the money allocated to them is spent, then this is usually referred to as ‘self-directed support’. Such terminology has been chosen over terminology such as ‘community-based services’ to make clear that these services support people to live as full citizens rather than expecting people to fit into standardised models and structures.

Why this is the right thing to do

Supporting disabled people to live in the community as equal citizens is an issue of human rights. The segregation of disabled people in institutions is a human rights violation in itself. Furthermore, research has shown that institutional care is often of an unacceptably poor quality and represents serious breaches of internationally accepted human rights standards. The European Parliament's 1996 Resolution on the Rights of Disabled People called on the European Commission and Member States to promote the social inclusion of people with disabilities and advocated non-discrimination and non-violence against people with disabilities. It proposed that disability rights be treated as a civil rights issue, that institutionalization should be avoided and that no-one with disabilities should be institutionalized against their will. The Charter of Fundamental Rights of the European Union (2000) prohibits discrimination on grounds of disability and says that the European Union should respect the right of persons with disabilities to benefit from measures designed to ensure their independence, integration and participation in the community. The United Nations Convention on the Rights of Persons with Disabilities (which the European Community and member states have signed, although not yet ratified) includes the right to independent living and participation in the community (Article 19).

Evidence from research and evaluation of alternatives to institutional care also supports this change. Where institutions have been replaced by community-based services, the results have generally been favourable. A very large number of research studies overwhelmingly show better results for people receiving services, their families and the staff supporting them[2-6]. However, experience shows that moving to community-based services is not a guarantee of better outcomes: it is possible to inadvertently transplant or recreate institutional care practices in new services[1,2]. Developing appropriate services in the community is a *necessary*, but not a *sufficient*, condition for better results[3].

Good community-based services are organised on the basis of certain principles:

- They are *person-centred*. That is, they are tailored to the individual's needs, wishes and aspirations, providing assistance in whatever way best helps the person achieve their own goals and adapting the kind and level of support as required over time.
- They *support family and community life*. They provide extra help to the person, their family and friends to enable them to live in and be part of their community, augmenting their resources rather than displacing or disrupting them.
- They adopt *a social model of disability*. They recognise that the experience of impairment is mediated by social structures and processes and address these.
- They *address all of people's lives*. They provide whatever help is needed to overcome the effect of impairment and disability to enable people to have a good quality of life. They do not pretend that people can manage without extra help.
- They *ensure these principles are expressed in the day-to-day assistance provided to the individuals they support*.

The contribution of this project

In 2003 the Commission funded the project *Included in Society*, which was carried out by a consortium of European non-governmental organisations. This showed that there were very few data on the number of disabled people in institutions. It also showed that existing large institutions provided very similar care to those studied in the nineteen-seventies, and that this was much worse than was already being achieved in community-based services. This led the Commission to identify as a priority the practical considerations of how to support Member States making the transition to community-based services, including managing the costs of doing so. The common challenge across Europe is how to organise community services for disabled people so that their independence, integration and participation in the life of the community is successfully achieved; and how to manage the transition from institutionally-based systems of care to new models in the community.

The current project was funded through the Community Action Programme to combat discrimination, adopted in 2003. In particular, the first theme of this programme focuses on strengthening the analysis of the nature and consequences of discrimination. The project was developed to reinforce the European Union's capacity to anticipate and manage change, acting as a catalyst to bring about policy developments contributing to the elimination of discrimination on the grounds of disability.

The project was carried out by a consortium of partners drawn from across Europe, supported by a Reference Group and links with existing scientific networks. Details of the Consortium are given in Appendix 1.

Purpose of project

The overall aim of the project was to provide scientific evidence to inform and stimulate policy development in the reallocation of financial resources to best meet the needs of people with disabilities, through a transition from large institutions to a system of community-based services and independent living.

The objectives of the project were to:

1. Collect, analyse and interpret existing statistical and other quantitative data on the number of people with disabilities placed in large residential institutions (institutions where more than 30 people live, of whom at least 80% were disabled), including the type of disabilities concerned, the age and gender of residents, the nature of the services received and the number, type and qualification of staff involved, in 28 European countries.
2. Analyse the economic, financial and organisational arrangements necessary for an optimal transition from a system of large institutions to one based on community services and independent living, using three countries (England, Germany and Italy) as case studies to illustrate the issues involved. This phase included
    (i) Specification of the roles of national, regional and local public authorities, disabled people, their families, their representatives, staff organisations and non-governmental organisations
    (ii) Consideration both of the comparative costs of institutional versus community-based services and of the transitional costs involved while replacing institutions with alternatives
    (iii) Clarification of the costs falling on public and other bodies and also of the costs to private individuals (eg disabled people and their families) in so far as this was relevant, including differential effects on men and women.
3. Report on the issues identified in 1 and 2, in a form suitable for stakeholders and policy-makers, together with an executive summary targeted at the general public that can be incorporated into the second regular report of the Commission on the situation of people with disabilities. In addition to the results of the project, the report would specifically address
    (i) The adequacy of the data available in each country, including its completeness, consistency and comparability
    (ii) Recommendations for the cost-effective transition from institutions to community-based services, identifying different strategies for different groups of disabled people or different Member States where relevant.

The project is therefore concerned as much with framing the tasks and challenges that have to be addressed as with reporting on the available evidence. Previous research has shown that the data needed for countries to address their responsibilities is patchy and incomplete. Part of the function of this project is therefore to map what needs to be done to enable countries to pursue the goal of equal rights for disabled people.

Structure of the report

The next section of the report describes briefly the methods used in each part of the project. The findings of the project are then presented in four sections. The first of these presents the results of Phase 1 and deals with the review of European and international data sources, the identification and collation of existing national data sources, their analysis and clarification of the adequacy and completeness of the data. Detailed information on individual countries is presented in Volume 3 of the report.

The second set of results is a brief overview of the sequence and process of service development in the three countries selected as case-studies and a commentary on the roles of different actors in the process. This section aims to identify major themes in the process of service development preparatory to considering the economic evidence.

The report then provides findings on the comparison of the costs of community-based vs. institutional services. This section deals with the barriers and facilitators faced by decision-makers in undertaking the replacement of institutions with services in the community, reviewing the available European evidence and identifying the issues which need to be considered if the transition is to be carried out well.

The last section of findings looks at the dynamics of change as the process of service development unfolds. It identifies the transitional cost (eg ‘double-running’) issues and illustrates how costs change over time. As the balance of care alters, so will the relative costs of different settings, because the people who move from one location to another are often not typical of the populations from which they move or to where they move. The immediate consequences of change, therefore, can themselves be both boon and burden.

The final section of the report presents conclusions and recommendations arising from the whole project.

2. Method

Defining the scope of the project

Concern about the quality of care for disabled people living in residential settings has mainly focused on establishments characterised by large size (ie substantially larger than family or communal living circumstances), the congregation of people with disabilities together and isolation from the wider community. Studies of the care provided in establishments have emphasised depersonalisation, social distance, block treatment and rigidity of routine. For the purposes of this study, the European Commission defined a residential institution as an establishment in which more than 30 people lived, of whom at least 80% were mentally or physically disabled.

A major issue in the transition from institutional to community-based models of care is the provision of sufficient services in the community *before* institutions are closed. Therefore as well as collecting information about establishments where more than 30 people lived, informants were asked to supply information about all residential care establishments serving disabled people in each country. This renders it possible to examine the current balance between institutional and community care.

The study covered all age groups but informants were asked where possible to separate information about children's, adult and older persons' services, so that meaningful comparisons between countries with different demographic profiles could be made. Similarly, the study covered all kinds of disability, including mental health problems.

Phase 1

Task 1: Review of European and international data sources and development of template for data collation

Existing sources of data were reviewed to identify material relevant to the study. These included official reports from Eurostat, WHO, OECD, ILO, relevant reports from non-governmental organisations (eg Inclusion Europe Country Reports, Mental Health Economics European Network Country Reports) as well as specific studies of the issues eg [4,5]. This work was carried out by a project worker jointly supervised by the University of Kent and the London School of Economics. It led into the production of a template to guide the collation of data from each country. The template was developed by Prof Jim Mansell and Dr Julie Beadle-Brown in consultation with the other experts.

Task 2: Identification and collation of existing national data sources

In order to secure access to existing national data sources partners each took responsibility for working with a small group of countries. For each country, contact was made with the relevant government departments to identify possible sources of data, using both the advice and assistance of the Commission and existing professional networks (such as the Mental Health Economics European Network and the Special Interest Research Group on Comparative Policy and Practice of the International Association for the Scientific Study of Intellectual Disability).

The allocation of responsibility between partners for collecting national data was as follows:

Partner	Countries for whom responsible
University of Kent, UK	UK, Ireland, Denmark, Malta, Sweden and Finland
University of Siegen, Germany	Austria, Germany, Lithuania, Latvia, Estonia, Slovakia and Slovenia
PSICOST, Jerez, Spain	Spain, Portugal, Italy, Greece, Turkey and Cyprus
Charles University of Prague, Czech Republic	Czech Republic, Romania, Poland, Hungary and Bulgaria
Catholic University of Leuven/EASPD	Belgium, France, Netherlands, Luxembourg

Although allocation of responsibility for national data collection needed to be clear for effective project management, one of the strengths of this project was that the consortium members had overlapping contacts and networks through their previous work. Thus they had multiple possible points of contact and sources of information.

Task 3: Clarification of definitions used in different data sources

Within each country it was important to identify as precisely as possible the definitions which were being used to underpin the collection of statistics. The research workers therefore interviewed informants in each country (by email, telephone or visit) to clarify:

(i) Definitions of groups of service users in institutions, using the International Classification of Functioning, Disability and Health as a template onto which national definitions can be mapped, providing a coherent single system of definition of the groups of service users involved.

(ii) Definitions of types of residential establishment. Rather than impose definitions *a priori*, informants were encouraged to describe in their own terms the different types of residential service provided.

(iii) Definitions of staff qualification types, based on level of education required, specialism and professional affiliation.

Task 4: Collation of data

Research workers employed by each partner collated the data obtained from each country from existing sources. The type of data collected (where possible) included the number of people in institutions, the main disabilities and age groups served in the institutions, the numbers and level of training of staff, the structure and organisation of the service system in general, and the financial mechanisms for funding care. A template was provided for this data collation, which was sent to each partner to guide their extraction of data from existing data sources and to ensure that data came back to the co-ordinating partner in as consistent a form as possible from each country.

Task 5: Check on completeness and quality of data

Data from each country was examined to assess, as far as possible, its internal consistency, so that queries and possible problems could be explored with informants. Informants in each country (including official sources and also contacts through the consortium's networks and reference group) were asked for their views on the accuracy, reliability and validity of the data sources used. Data were cross-checked against epidemiological and survey sources where these were available. Although the rate of institutional care varies across countries [6,7], cross-national comparisons were undertaken to identify potential areas where further work might be required.

Phase 2

This Phase of the project was carried out by the London School of Economics and the University of Kent. Expert advice was provided by Professors Martin Knapp and Jim Mansell and Dr Julie Beadle-Brown. The work was carried out by a project worker (Robert Hayward) and other members of the departments involved.

Task 1: Description of the sequence and process of service development

Three countries were proposed for case studies – England, Germany and Italy. England and Italy have made substantial progress in replacing institutional care of disabled people with community-based services and independent living. They are mature systems which have been the subject of much research and about which a great deal is already known [8,9]. Both have extensive evidence bases from which to work and have documented high-profile successes as well as failures from which important lessons can be drawn. Both of these countries have tax-funded health and social care systems although represent examples of different welfare-state types[10] – the United Kingdom as a liberal type and Italy as a conservative type. Germany was chosen as a country that is not so far along the path of deinstitutionalisation but which has had some successes. More importantly Germany has different health and social care funding mechanisms and a different service development history. Between them, these three case studies illustrate the different approaches necessary in systems of varying kinds to achieve successful deinstitutionalisation and community living. The German situation was examined using detailed analysis of the data from two federal states in particular (Nordrhein-Westphalia as a West- and Brandenburg as an East-German federal state); the Italian experience was examined by focusing on Campania, Emilia-Romagna and Veneto. This material was reviewed and a description of the sequence and process of service development in each country compiled.

Task 2: Identification of the roles of different actors in the process

As part of this review, particular attention was paid to the roles of different actors in the process. The following issues were important in this area:

(i) The relationship between national, regional and local tiers of government in the process, in terms of leadership, co-ordination and management of financial flows. This included gathering information on the governance structure of health and social care systems mapping the mixed economy of welfare (provider types and funding routes) as it existed in each of the three case studies.

(ii) Changes in the respective roles of tiers of government at different stages in the process (eg the transfer of responsibility from national to local level in Sweden and the UK and attendant issues of de-differentiation [11]).

(iii) The role of disabled people, their families and representatives in promoting, guiding and supporting the transition from institutional to community-based services.

(iv) The role of staff and their organisations in responding to changes in policy and practice, including the development of new occupational groups, training and qualification.

One focus for the work on the identification and interpretation of roles was the examination of the economic barriers to, and opportunities for, the movement from an institution-dominated system to one characterised by emphasis on community-based options that empower individual people with disabilities.

Task 3: Comparison of the costs of community-based vs. institutional services

Appropriate cost comparison between settings requires a methodological approach that ensures that all relevant resources are identified, their costs calculated, and the resultant figures interpreted in light of the characteristics of service users, the quality of care and (where possible) the outcomes they achieve[12,13]. This previous work has demonstrated methodologies for such an approach, and there is now a fairly extensive body of research identifying the range of relevant cost elements, their contribution to overall costs, and their associations with the characteristics of service users and settings, and other factors. These studies were reviewed to bring together a coherent overview of the cost comparison. It was important to look not only at the cost consequences of deinstitutionalisation, but also the cost-effectiveness of community care, of particular relevance where institutional care is of poor quality and inexpensive. Therefore data were collected where available (for example, from completed studies, government or other reports) on the comparative cost-effectiveness of institutional and community care for people with disabilities, looking not only for information on the resource implications of institutional and community options but also their quality and outcomes for users and (where appropriate) outcomes for families and the wider society.

A systematic literature review (using mainly electronic searching but some hand searching was carried out, starting with the economics evidence for England, ranging over all relevant service user groups, and then repeated for Germany and Italy. The evidence base for these latter two countries is much less plentiful. The search strategy was deliberately broad as the evidence was not expected to be especially well or precisely identified by key words or abstracts. In addition, a number of experts in the area in each country were consulted, asking for their help in locating evidence, especially that which might be missed by electronic literature searches. The names of those experts who were able to assist us are listed in the acknowledgments.

As part of this process attention was also paid to the comparison of services in three respects, to ensure ‘like for like’ comparison:

(i) Taking account of the level of disability of residents and therefore their needs for and receipt of services, to ensure that differences in cost are considered after adjustment for such factors

(ii) Taking account of the range and level of quality of services achieved, so that their influences on cost are understood

(iii) Taking account of the balance between costs met by public agencies and those met by others, especially the families of disabled people, to ensure that cost differences do not simply reflect a shift in costs to or from informal carers.

Task 4: Identification of transitional cost (eg ‘double-running’) issues

Even if the closure of a hospital or other large institution might eventually release resources that could fund community-based and other services, the management of facility closure takes time and needs extra short-term resources. There could be both ‘hump costs’ – initial investment in the new community facilities to get them underway and to train to staff who will work in them – and ‘double-running costs’ to resource both the old and the new services in parallel for a few years until the old service has fully closed down. Transitional costs of this kind require the commitment of extra funds in the short-term, although subsequent savings might counter-balance them, and improvements in quality of life and other outcomes might be expected to justify them. The available evidence was examined to understand the extent to which ‘transitional resources’ of this kind were important, their management and their expected pay-offs.

Task 5: Analysis of political and economic strategies used to manage costs

The different strategies used in each of the three countries used as case-studies to manage the cost and wider economic issues arising during the transition from institutional to community-based care were examined. These included:

(i) Increases in expenditure on institutional care to improve standards;
(ii) Mechanisms to incentivise the development of new models of service such as ‘dowry payments’, access to social security and other benefits, and strategies to address ‘welfare trap’ disincentives.
(iii) Transitional or ‘bridging’ finance to sustain institutions while developing community services, and to subsidise community systems of care as they gradually mature to full capacity
(iv) Attempts to more closely target resources on the basis of the needs of disabled individuals
(v) “Whole systems working” (including joint planning and commissioning) to bring together different providers and funding bodies which might otherwise not coordinate their efforts in the best interests of service users and communities
(vi) Person-centred services (person-centred planning, direct payments, personal budgets, etc) to empower service users within community-based systems of support.

Phase 3

The interim report, final report and executive summary were prepared by University of Kent and the London School of Economics. Interpretation of the results and their implications was strengthened by using the reference group as a ‘sounding-board’ and by discussion of the draft report with participants and with the European Commission.

3. Service provision for people with disabilities

Availability of data

Review of European and international statistics showed that there were no existing sources providing comprehensive information about the number and characteristics for people in residential institutions in Europe. Eurostat provides some information on numbers of psychiatric hospital beds but not on whether residents are people disabled by long-term mental health problems in each country. It does not provide information on services for people with other disabilities. United Nations statistics provide some information about number of people with disabilities but not on residential services for them. The World Health Organisation (WHO) has produced an atlas of mental health and is currently producing an atlas of intellectual disability. Contact was made with the project workers involved but the atlases provide only very broad information about each country. Indeed the results of this project are likely to be an important source for the WHO work.

Useful information about residential institutions was found in the country reports of some European non-governmental organisations, particularly those of Inclusion Europe in respect of intellectual disabilities. The Included in Society project also presented some information about numbers of people in residential institutions, but this relied on self-report by institutions and is unlikely to be comprehensive in coverage.

Individual countries varied in the extent to which (i) key informant(s) could be identified who were willing to help provide or access the data required (ii) there was already data available at national level, and (iii) information on the definitions used and the quality and completeness of the data was available.

Members of the European Union High-Level Group on Disability were presented with information about the project at the outset and also received a progress report in February 2007. With their help, key informants were found in 26 out of the 28 countries taking part in the project (see Appendix 2). It was not possible, despite repeated efforts, to identify anyone in Greece or Cyprus who could help with the project. Some limited information about Cyprus was obtained from published sources.

National data, albeit of limited coverage, was found in 23 of the 28 countries. In addition to Greece and Cyprus, no national data was available for Malta or Austria. In Austria, information was only available at regional level and no national collation could be provided. Although some national data existed for Germany, it did not exist in a form which could be easily collated for this study – actual number of places and information on disability, age etc was only available for one service type for older people, and national level data was only available at the level of the number of people receiving financial assistance and not how the money was used.

Clarification of definitions and completeness and accuracy of the data was achieved in the five countries in which researchers were based by direct contact and their expertise; in addition, researchers interviewed officials in 13 other countries.

In general, it was very difficult to obtain comprehensive national data. Typically, different government agencies were responsible for services to different client groups or for different kinds of services. There was not usually a single point of contact who could provide an overview of the data required. In many countries, some data was not collated at national level even where it did exist at regional or local level and in some countries (such as Austria or Germany) this meant that were was almost no national information about deinstitutionalisation and community living of disabled people. Where data was available, there was generally little evidence of standardised definitions and classification, so that it was not possible to be confident that information from different sources within each country, let alone between different countries, was completely comparable.

Completeness of the data

Table 1 reports the completeness of the data on number of places available and the size of establishments available in each country. It shows that the availability of data is very uneven within and between countries. The country reports in Volume 3 give a detailed breakdown of the availability and nature of data in each country.

Table 1 Completeness of data on number of places and size of each type of service

Country	Year[1]	Places	Size
Austria		No data at national level - limited information at regional level	
Belgium	2005	Almost complete data but did not include data on Brussels. No data available for one service type listed (SRT). Although not all types residential institutions were included (eg psychiatric institutions appear to be missing from the template), data on size. Accuracy and completeness of official statistics was checked with people locally.	
Bulgaria	04/05	Almost complete data available for 11 out of 13 service types listed – no data on places for psychiatric wards, psychiatric hospitals or social vocational boarding schools.	Data on size known for all except 300 of the 14138 places recorded.
Cyprus		No national level data and no contacts to check accuracy of informal sources	
Czech Rep	04/05	Data on number of places available for all service types listed	Data on size of residential institution only available for specialised psychiatric institutions.
Denmark	2005	Number of places known for all 15 service types listed. Does not appear to include psychiatric institutions.	No data on size of institutions.
Estonia	2005	Data on number of places in five of six service types identified. No Psychiatric institutions included.	Almost complete data on size for four service types with very limited information on size for wards or units in general hospitals
Finland	02/05	Data on number of places for five of the 12 service types	No data on size of residential service
France	2005	Data on number of places available for children but not	No data on size of service available

Country	Year[1]	Places	Size
		broken down by type of service and for four of seven adult services. No data on psychiatric hospitals or smaller community based services included.	
Germany	03/07	Data only available for one service type - a nursing home mainly for older people without pre-existing disabilities. Official data on other service types was considered too inaccurate/incomplete to include in the template.	
Greece		No official data available – no official contacts identified	
Hungary	01/04	Data on number of places provided for three out of six service types identified.	Some very limited data on size was available but was unclassified for most service types.
Ireland	03/06	Data available from registers on number of people not places. 23 service types identified and data on number of people in these service types. However likely that some data was missing as less than 9400 places identified. Data likely to be missing on mental health services.	No data on size of service available
Italy	03/05	Data on number of places available for all 19 service types identified - four of these service types appear to be for older people but the residents of these places are identified as having mixed disabilities and it is unclear whether they had pre-existing disabilities or age related disabilities.	Complete data on size for 15 of these service types and almost complete data for one more service type.
Latvia	04/06	Number of places provided for 13 out of 15 identified service types.	No data on size provided
Lithuania	2005	Data on number of places in all eight service types identified (one for older people but identified as for older people with mixed disabilities).	Almost complete data on size for six of these service types – size of rehabilitation and psychiatric hospitals not identified.
Luxembourg	2006	Complete data for all 11 service types identified.	
Malta	06/07	No national level data available but data received directly from institutions and from individual contacts. Likely to be incomplete as sources varied. Three of the service types identified were just for older people and so are not included in analyses.	Data on size for two of the four service types identified for people with disabilities
Netherlands	2005	Data on number of places available for 10 of the 11 service types available (but not for	Data on size for six of the service types identified and only for those which are smaller services. No

Country	Year[1]	Places	Size
		living forms for people with intellectual disability).	data on size for "larger living forms").
Poland	2005	Data on number of places in six service types.	No breakdown by size available.
Portugal	06/07	Data on number of places available for 13 of the 15 services available	Complete data for 12 of the 13 services.
Romania	2006	No data for children's services. Data available on number of places for the eight services for adults.	Almost complete data on size for five service types. Some data for two other types.
Slovakia	2005	Data on number of places available for 10 out of the 13 service types identified but two of these appeared to be just for older people - difficult to confirm as no breakdown for disability provided for these service types.	Almost complete data on size for six of the service types (not including those for older people)
Slovenia	99/00	Seven service types identified but data on number of places only for two types	No breakdown by size even for the two services for which some data existed
Spain	06/07	Data on number of places available for 15 of the 16 service types identified but one of these was a geriatric hospital for which it wasn't clear whether people had a pre-existing disability.	Complete data on size available for six of these service types – mainly the smaller services.
Sweden	05/06	Data on the number of places in the three service types	No breakdown by size available
Turkey	2007	Number of places provided for seven out of the eight service types identified.	Almost complete data on size for six of the service types.
UK	02/05	14 service types identified and data on number of places available for 13 of these. However, data for some of children services includes places for children with emotional and behavioural difficulties. Six service types provided for older people without disabilities – only places for those with disabilities included in the analysis.	Almost complete data on size available for four service types and for services in England but breakdown by size not available for data from Scotland and Northern Ireland.

[1] Where more than one year is given, e.g. 03/07, this indicates that data collated is from more than one year, with in this case data being collated from 2003 to 2007. The second year indicates the most recent source of data used.

Table 2 presents information about the completeness of information at national level about the principal type of disability of residents, their age and gender. Here too there is a picture of patchy and incomplete information. For example, Estonian data can be broken down by age group (children, adults or older people) for some service types but not others. Similarly, Czech data can only be broken down for different disability groups in a few of the service types listed. In some countries the data is available for people rather than places – in Ireland, for example, there are intellectual and physical and sensory disability registers which informs as to the characteristics of the people and the name of the services used but does not provide any further information on the nature of that service in terms of size. There is no such register on mental health as yet and as such, data for Ireland, as for other countries is collated from a variety of different sources. As can be seen from the table, data on mental health services was particularly incomplete or missing altogether.

Table 2 Completeness of data on disability, age groups and gender of people served

Country	Disability	Age	Gender
Austria	No data at national level - limited information at regional level		
Belgium	Complete data on three/nine service types – all for intellectual disability . Only 1477 mental health places and 550 physical or sensory disability places identified. No information on disability group for two service types.	Complete data on four service types three for adults over 18 with intellectual disability, one for children. Partial data for three other services.	Almost complete data on gender but no data for Brussels.
Bulgaria	Complete breakdown for nine of 14 service types, mainly services for intellectual disability. 869 places (one service type) for those who are elderly and infirm/dementia	Complete data for eight service types and partial data for one other service type – Adults not usually divided up into older and younger adults.	Data on gender known for all except 465 of places recorded .
Cyprus	No official data available – no official contacts identified		
Czech Rep	Complete data on disability only available for three of the 14 service types. Very limited data available for psychiatric institutions.	Complete data on age group for psychiatric institutions and almost complete data on older peoples homes – otherwise no data on age breakdown.	Data on gender only available for two of the 14 service types.
Denmark	No breakdown by disability group.	Complete breakdown by age group for all 15 service types listed.	No data on gender of residents.
Estonia	Almost complete breakdown by disability for two service types and partial data for two	Complete data on age for three service types, partial for two others.	Almost complete data on gender for two service types and limited or no data on

Country	Disability	Age	Gender
	others. Only 940 places for mental health identified.		gender for other four types.
Finland	Complete data on disability for six out of 12 service types. No data on physical or sensory disability and majority of data on intellectual disability – 5500 places identified for mental health.	Complete or almost complete data on age for only three service types, all for people with intellectual disability.	Good data on gender available for three service types but not for others.
France	Breakdown by disability only available for children across all services not in different types of children services. But data basically complete. Almost complete data on four other services.	Breakdown for children and adult only – very little breakdown between younger and older adult services. Complete data on age breakdown for two services only.	Good data on gender available for four service types (for adults). No data on gender for children.
Germany	No data apart from nursing homes which were primarily for older people.	Complete data for one service type – nursing homes – the majority of places (650,000) being for older adults (over 60). Some places for younger adults (31,000) and children (2410).	Data only available for one service type - a nursing home mainly for older people without pre-existing disabilities. Official data on other service types was considered too inaccurate/incomplete to include in the template.
Greece	No official data available – no official contacts identified		
Hungary	Almost complete data on disability for three out of six service types listed – mainly classed as mixed diagnoses – ie more than one disability groups cater for in each service types.	Almost complete data for three of the service types.	Good data on gender was available for two services with only 459 out of 24400 places recorded.
Ireland	Complete data on disability for 17 out of 23 service types. Almost complete data for one service type. However, no places for people with mental health identified.	Complete data for 13 service types. Almost complete data for – able to break down older and younger adults. Also some info for children – 317 children included.	Almost complete gender data was available for most services with data on gender unspecified for 463 people out of 9369.
Italy	Complete data for two service types. Partial data for most other service types – no data specific to people with	At least partial data for all but two service types. No complete data on age group.	Complete data on gender available for eight of these services.

Country	Disability	Age	Gender
	intellectual disabilities – they are included with those with mixed/dual diagnoses. More data for mental health and physical or sensory disability.		
Latvia	Complete data on disability group for seven out of 15 service types. Almost complete data for another two service types. Largest disability groups were classed as mixed/dual and other.	Complete data on age group for 13 out of 15 service types.	Complete data on gender for nine of the 13 services for which data available.
Lithuania	Complete data on disability for four of eight service types and almost complete for another one service type. However most places classified as for mixed/dual diagnoses – no data on intellectual and only 2814 mental health and 805 physical or sensory disability.	Complete data on age for three service types and almost complete for another three. Breakdown between younger and older adults possible.	Almost complete data on gender for all service types – gender unknown for only 2043 of the 50,581 places identified.
Luxembourg	No breakdown by disability group	Complete data for all 11 service types.	Complete data for all 11 service types.
Malta	Only three of six service types of people with disabilities (other three of elderly infirm)	Data on age available for two of the three disability services.	Data on gender for just one of disability services.
Netherlands	No breakdown by disability group	Complete data on three out of 11 service types and almost complete data on a further three. Where data was available it did allow breakdown between younger and older adults.	Complete data on gender for two of the service types – no data on gender for the other service types.
Poland	Partial data on disability group available for two out of six service types. No data on places for those with mental health needs although one service type appears to be specifically for those with chronic mental illness.	Almost complete data for four service types – breakdown between younger and older adult possible. No breakdown for two types.	Almost complete data (only 1% unclassified) on gender for four of the service types.

Country	Disability	Age	Gender
Portugal	Complete data on 10 of 15 service types. No data on physical or sensory disability – may be included in mixed/dual category.	Complete data on age groups for six service types. Partial data on another two service types.	Complete on gender for only three of the smaller service type and partial data on one other service type.
Romania	No data for children. Complete data on disability for two service types, almost complete data for one service and partial data for three further services. Data on all disability groups.	No information on children at all. For adult services, there was complete data for five of eight services.	No data on gender
Slovakia	Complete data on disability group for three from 13 service types. Almost complete data for a further two services. No specific data for intellectual disability and mental health groups – mainly physical or sensory disability and mixed/other places. Two services for older people.	Complete data on age group for five service types; almost complete data for another three types and partial data for one further service type.	Almost complete data on gender for eight of the service types and limited data on one other service type.
Slovenia	No breakdown of limited data available by disability or age group.		
Spain	Complete data on disability group for nine of 16 service types. Only 2948 places for people with mental health needs identified.	Data on age group only available for services for older people with disabilities.	No breakdown by gender.
Sweden	No breakdown by disability group	Complete data for two of three service types identified.	Complete data on gender for two service types and reasonable data for the other service.
Turkey	Complete data on disability group for five of eight service types identified. Almost complete for one further service types. No data on mental health.	Complete data for six service types and partial data for one further service type. Younger and older adults not distinguished.	Complete data on gender for six service types.
UK	Complete data on disability group available for four out of 14 service types, almost	At least partial data available for 13/14 service types but only at limited level of care	Complete data on gender only available for two types of children's services but

Country	Disability	Age	Gender
	complete data for one type and partial data for five other service types – more data on disability group for England than for other three countries. Some of places only for older people without pre-existing disabilities – these places not included in the analysis.	home registration for the most part – ie for younger adults or for older adults.	without breakdown by disability.

Table 3 shows the completeness of data on staff numbers and training. Data on staff numbers appears relatively complete for Belgium, France, Italy, Latvia, Lithuania, Luxembourg, the Netherlands but information on training is only of comparable quality in Belgium and the Netherlands.

Table 3 Completeness of data on staff numbers and training

Country	Staff numbers	Staff training
Austria	No data at national level - limited information at regional level	
Belgium	Data on numbers and breakdown by type of staff for seven of the nine service types listed.	Almost complete data on staff qualifications for three of nine services.
Bulgaria	No data on staffing	
Cyprus	No official data available – no official contacts identified	
Czech Rep	No data on staffing	
Denmark	Data on numbers for one service type only	No data on training
Estonia	Almost complete data on numbers and type of staffing for four out of six services.	No data on training
Finland	No data on staffing	
France	Complete data on numbers and type of staffing for 10 of 13 service types.	No data on training
Germany	Data numbers and type for one service type (mainly for older people)	No data on training
Greece	No official data available – no official contacts identified	
Hungary	Data for two out of six service types on numbers and type of staffing	No data on training
Ireland	No data on staffing	
Italy	Complete data on staff numbers and type of staff for 18 out of 19 service types	No data on training
Latvia	Data on numbers for nine of 15 service types. Almost complete data on type of staffing.	Some partial data on training.
Lithuania	Almost complete data on number of type of staff for all eight service types.	No data on training

Country	Staff numbers	Staff training
Luxembourg	Data for numbers of staff for nine/11 service types.	Partial data on training
Malta	Very limited data on numbers only for two service types.	
Netherlands	Data on numbers of staff but not by type of staff for four out of 11 service types.	Almost complete data on training for four/11 services.
Poland	No data on staffing	
Portugal	Complete data on three/15 service types for both number and type of staff	No data on training
Romania	No data on staffing	
Slovakia	Data on number of staff for nine service types and almost complete data on type	Partial data on training.
Slovenia	No data on staffing	
Spain	Data on only one service type with numbers and type of staff.	No data on training
Sweden	No data on staffing	
Turkey	Almost complete data on number and type of staff for six out of eight service types.	No data on training
UK	Data on numbers and type of staff for children's homes only – no data for adult services.	No data on training.

Problems of incomplete data largely reflect underlying structures of service provision and different expectations and practices of information-gathering. Regionalisation means that some data are not collated at national level even if they exist at subordinate levels of government. Services provided or funded by different government agencies tend to have different practices concerning reporting statistical information, so that it is difficult to aggregate data. In some countries data is collected about the number of places available in residential services but not about the people actually occupying them; in others there is information about the numbers of people served but not about the nature of the services they live in. It should also be remembered that however services are classified in terms of the client group they are supposed to serve, there will be wide variations in the extent to which DSM or ICF criteria are actually used in practice. Therefore services for one group may in fact include people from other groups.

Types of residential service

Researchers obtained descriptive information on each different type of residential service provided in each country for people with disabilities. Disabilities groups which were generally included were physical and sensory disabilities, mental health problems, and intellectual disabilities. As far as possible services providing only those with chronic or acute illnesses, emotional, behavioural or learning difficulties, substance abuse problems and those who were older with no pre-existing physical, intellectual disability or mental illness were excluded. However, in some cases (eg the UK) this differentiation was hard to make – eg children with behavioural and emotional disorders and those with special educational needs are often classed as "disabled" in statistics on residential provision for children. It was necessary to estimate the numbers of people with disabilities from broader categorisation of problems experienced. It is also acknowledged that there are people with disabilities in services for each of these excluded groups and therefore numbers presented below represent those people in services for mainly serving people with disabilities – a relatively substantial minority of people may be missing.

Only services providing at least some long-term residential support were included (for example, services which only provided acute psychiatric treatment or short-term breaks for families supporting disabled people at home were excluded). It has to be acknowledged that in some countries such as Sweden and the UK, supported living and personal budgets were the main or an important form of provision and were also emerging in Germany, Estonia, Spain and Italy to name a few. These new paradigms are not included in the figures presented below but where data does exist on the numbers of people accessing supported and independent living, these figures are provided in the country reports in Volume 3.

Very few countries reported typical service models that were very small (1-5 places). In some of these countries (for example Sweden and the UK) the boundary between small residential homes and high levels of support in the person's own home is becoming blurred. Access to housing is increasingly being enabled on the same terms as for the rest of the population, with whatever help is required then being provided in that setting, even for people with the most severe and complex needs.

Just over half the countries studied provided residential services that were typically in the size range 6-30 places. Thirteen countries reported this in respect of services for people with intellectual disabilities; the next largest number (11) was in respect of people with different disabilities mixed together. Larger establishments – those of over 30 places – were reported as the typical form of provision for at least some user groups in 21 countries. Generally speaking, in those countries which have already made substantial progress in deinstitutionalisation and community living, mental health facilities were reported as typically larger than those for other defined client groups and schools and colleges were reported as typically larger than other types of service. In some other countries, large institutions were reported as typical for most client groups. Summaries of the information for each service type in each country is provided in the country reports (Volume 3).

Despite the differences between countries illustrated above and in the country reports, it was possible to identify six main types of services into which all services generally fell:

- Group homes: typically 5-6 people living together, though some examples may have up to 10 people resident. In some situations these are provided for people with mild or moderate disabilities but in others they are provided for people with more severe disabilities or complex needs (such as people with severe and profound intellectual disabilities whose behaviour also presents a major challenge, or people needing intensive nursing care). Staff support varies from visiting or drop-in support to 24-hour cover, depending on the needs of residents.

- Residential homes: typically between 10 and 30 places, usually providing 24-hour staffing. In some countries these kinds of home may also provide nursing care but the ethos of the home is as a residential care setting providing a substitute home.
- Campuses: group homes clustered together on the same site and usually sharing staff and some facilities. Staff are available 24-hours a day.
- Residential schools for disabled children and colleges for young adults: these services are not distinguished by their size – they vary from establishments providing about 10 places to those providing for several hundred – but they are organised as schools or colleges providing education alongside residential care.
- Social care homes or residential institutions: large establishments serving more than 30 residents (sometimes many more residents than this). Sometimes these establishments serve people with one type of disability but some serve people with different disabilities (and sometimes people who are not disabled at all) within the same establishment.
- Hospitals or nursing homes: typically larger establishments, usually over 30 places, organised primarily around medical and nursing practices and providing 24-hour staffing.

Table 4 summarises the provision and funding of institutional provision for service types for which detailed descriptions were available. In 16 of 25 countries for which info was available, state funds were being used at least in part to support institutions of more than 100 places. In 21 countries state funds were being used to support institutions of more than 30 places (state funding includes local or regional government funding). In 12 (of 25) countries provision which was typically smaller (1-30 places) was being provided by the state although in many cases this was very limited - with the majority of such provision in most countries being by non-governmental organisations. In 17 countries smaller provision was being provided by non-governmental organisations. In six countries there appeared to be no provision typically smaller than 31 places and for Greece, Cyprus, Austria and Denmark there was no information provided on the size of services.

Table 4 Summary of provision and funding of institutional provision for all service types for which detailed descriptions available

Country	Service types > 30 places	Provided by State/ LA/RA	Funded by State/LA/RA
Austria	No data		
Belgium	Yes, 5/8 service types	No	Yes, 4/5 types. 1 service type (ID) over 100 places
Bulgaria	Yes, 12/13 service types	Yes all	Yes/all 5 service types (All disability groups) over 100 places
Cyprus	No data		
Czech Rep	Yes, 1/9 service types for disabilities (no info on bigger services eg	Yes	Yes 1 service type (Mixed disabilities) over 100 places.

Country	Service types > 30 places	Provided by State/ LA/RA	Funded by State/LA/RA
	social care institutions)		
Denmark	No data on typical size, but almost all service types provided and funded by LA/Municipality.		
Estonia	Yes 5/7 types	Yes - Mixed provision but some State provided	Yes, all funded by LA/RA 2 Service types (mixed disabilities) >100 places.
Finland	Yes, 2 out of 10 service types	Yes, LA/municipality with some independent	Yes both funded by state/LA/Municipality Yes 2 service types (ID and MH) > 100 places
France	Yes, 7 of 10 service types	No all independent provision	Yes, 3 of the 7 larger service types funded by state
Germany	Yes, 3 service types (plus one for older people)	Yes, Mixed provision but larger service types tend to be independently provided	3 of the larger service types can be funded by state/LA/RA. Other 1 funded through benefits/social security. 1 service type (PSD) >100 places
Greece	No template data		
Hungary	Yes, 5 of 8 service types	Yes, Mixed provision but some large services provided by state/LA	All state funded 1 service type (MH) > 100 places
Ireland	Yes 14 of 23 service types can be between 30 and 50 places (N.B. no data on psychiatric hospitals)	Yes, mainly state/LA or voluntary sector.	Mainly state
Italy	9 of 20 service types (between 30-50 places)	Yes, Very mixed provision but some service state/LA provided	Yes, Mixed funding but all but one of larger services do have State/LA funding.
Latvia	12 of 14 service types	Yes, Almost all state provided	Yes, All State or RA/LA funded 10 types (All disability types) > 100 places
Lithuania	6 of 8 service types (plus1 for Elderly infirm)	Yes, Mainly LA/RA/State provided	Yes, All have some state funding. 6 service types (All disability types) > 100 places
Luxembourg	2 of 11 service types	No, All independent sector	Yes, Mixed funding systems but includes some

Country	Service types > 30 places	Provided by State/ LA/RA	Funded by State/LA/RA
			contributions from state which are not as benefits to individuals. Both service types (for ASD and young adults with behavioural and emotional disorders > 100 places
Malta	1 service > 30 places plus 3 for elderly infirm not.	Yes	Yes 1 service for mixed disabilities over 18 > 100 places.
Netherlands	1 service type (for PD) listed as over 30 places but not consistent with other sources and no mental health services included.	No, all independent	Yes, all services are State or RA/LA funded. Number over 100 not known.
Poland	All 6 service types	Yes, Mixed provision including state. Two types are completely state provided.	Yes, Mixed pattern of funding - but some funding from State/LA. 3 types (ID and MH) >100 places
Portugal	2 of 8 service types (plus 2 for older people only)	No - all independent sector provision	Yes, Larger services tend to be provided by the State Both service types (ID with complex needs) > 100 places
Romania	8 of the 9 service types with data	Yes, all state/LA provided	Yes, Mixed pattern of funding – but some funding from State/LA.
Slovakia	5 of 10 service types (plus one for older people only)	Yes, mixed pattern of provision but the state/LA does provide some services	Yes, mixed pattern of funding but some of larger services funded directly by state/LA 2 service types (Mixed disabilities) >100 places.
Slovenia	On data on typical size provided for one service type – usually between 50 and 100 places - no other information available.		
Spain	5 of 14 service types	Yes, mixed pattern but larger services often provided by State/LA	Yes, mixed pattern of funding but larger service types funded by State. 3 service types (older people with disabilities, PSD, MH)

Country	Service types > 30 places	Provided by State/ LA/RA	Funded by State/LA/RA
Sweden	None service types greater than 30 places		
Turkey	5 of 6 service types	Data only on 1 service type which had mixed provision and funding. No services typically >100 places	
UK	4 of 16 service types (plus 1 for elderly infirm).	Yes, larger services a mixture of State (ie NHS) and private provision	Mixed funding – usually via benefits or private funding. Health based services funded by State. 2 service types typically >100 – Secure/forensic hospitals (Scotland) and NHS Campus settings (mixed ID with complex needs).

RA = Regional authority
LA = Local authority
ASD = Autistic Spectrum Disorders
PD = Physical Disability
PSD = Physical and Sensory Disabilities
MH = Mental health
ID = intellectual disability
Complex needs = severe physical disabilities, health problems, MH problems/challenging behaviour, autism.

Number of people with disabilities in residential provision

This section presents the data obtained from official statistical sources and, in some cases, other quantitative data sources from each of the countries involved in the study. These data are simply those available from each country; they are therefore known to be incomplete for the reasons already discussed. They are presented to provide a starting-point from which improvements in data collection and presentation can be made. The data are first presented by disability group, distinguishing by size of establishment, age of residents, gender and staffing.

Size of establishment

Table 5 shows the number of residents living in residential services in the countries studied. It shows that there are nearly 1.2 million people living in residential establishments for people with disabilities in 25 countries which could provide these data. For the great majority of these people, there is no data on the size of establishments in which they live. Even where such information is available, it is partial. For example, in the UK it was possible to get precise information about size for residential homes in England, but not in Scotland, Wales or Northern Ireland; and not for health services settings such as long-stay psychiatric hospitals. In France, number of places by size of setting was not available from official sources and the official data available for France does not appear to differentiate between “internat” (residential) and “externat” (day provision only). As noted in the country report, however, other sources of data imply that the figures provided below are an accurate reflection of those in residential care according to official data sources.

Table 5 Size of residential establishments summarised from official data classifications

Country	Places	Size<30	Size>30	Not classified
Austria				
Belgium	25750	5164	18130	2456
Bulgaria	13269	216	11540	1513
Cyprus	495			495
Czech	66865		9858	57007
Denmark	62081			62081
Estonia	22421	1805	7243	13373
Finland	18032			18032
France	224827			224827
Germany				
Greece				
Hungary	24390	1114		23276
Ireland	9369			9369
Italy	117241	14514	81428	21299
Latvia	10053			10053
Lithuania	45464	180	14924	30360
Luxembourg	704	410	294	0
Malta	642	88	544	10
Netherlands	64144	59450		4694
Poland	73741			73741
Portugal	11422	4427	6995	0
Romania	32783	214	28348	4221
Slovakia	12252	716	3142	8394
Slovenia	821			821
Spain	181636	2425	777	178434
Sweden	29578			29578
Turkey	9494	86	3127	6281
UK	129548	33530	48781	47237
Total	1186962	124339	235131	827492

Some of these data contradict evidence from other sources. For example, Buntinx[14] reported that in the Netherlands in 2002 there were 34051 places in residential establishments for people with intellectual disabilities, of which 22209 were grouped on ‘campuses’; and that the average size of establishment was more than 30 in 9 of 13 Dutch provinces. This suggests that national data in some countries may not adequately reflect actual service provision.

Age of residents

Table 6 shows the number of places in residential establishments classified by official sources as for children or for adults. In general the age of majority was 18 and figures here are the official figures where they could be broken down by age group, with the cut off between children and adults being 18 years of age where at all possible. However age group classification was not always consistent across countries and some services for children did provide for young adults – (eg 16-23).

Table 6 Age of residents as classified by official sources

Country	Places	Children	Adults	Not Classified
Austria				
Belgium	25750	6940	15036	3774
Bulgaria	13269	4752	6984	1533
Cyprus	495			495
Czech	66865	3292	38427	25146
Denmark	62081	23673	38302	106
Estonia	22421	1134	18163	3124
Finland	18032	418	9599	8015
France	224827	108903	81420	34504
Germany				
Greece				
Hungary	24390	1482	22449	459
Ireland	9369	317	8228	824
Italy	117241	1041	86933	29267
Latvia	13463	5819	7644	0
Lithuania	45464	5808	39195	461
Luxembourg	704	48	655	1
Malta	642	0	218	424
Netherland	64144	7153	52597	4394
Poland	73741	1957	39819	31965
Portugal	11422	1002	9074	1346
Romania	32783	611	17007	15165
Slovakia	12252	1600	8430	2222
Slovenia	821			821
Spain	181636		138354	43282
Sweden	29578	1315	27441	822
Turkey	9494	992	2269	6233
UK	129548	2445	98297	28806
Total	1186962	180702	766541	239719

On average, 15% of residential places are classified as for children in 21 out of 28 countries where some data was available. This average figure conceals some variation - sixteen countries reported less than 15% of residential places being allocated for children, with the remaining five reporting between 27% and 48%. Low levels of residential provision may reflect (i) low levels of service so that families support children at home without help, (ii) that children are placed in services intended for adults, or (iii) that families are provided with high enough levels of service at home to enable them to support their children without seeking residential placement.

Among the countries reporting much higher numbers, the French data should be treated with caution because of the inclusion of some people attending residential services during the day but not actually in residence. This is particular true of children's services. It is also important to note that breakdown by age is not known for around half of the places for Romania, Poland and Turkey and the number of places known to be for children is very low. It was not possible to extrapolate to more accurately estimate numbers of children in residential care in these countries, as not enough is known from other sources about the proportion of children to adults in residential care.

Gender of residents

Table 7 shows the number of places in residential establishments classified by official sources as for males (boys or men) or females (girls or women). In eight countries more than 90% of places had no information on gender. Where information was relatively complete (as in Sweden, Hungary, Lithuania, and Luxembourg) on average 53% of places were occupied by males.

Table 7 Gender of residents as classified by official sources

Country	Places	Male	Female	Not classified
Austria				
Belgium	25750	11150	9997	4603
Bulgaria	13269	4080	3797	5392
Cyprus[1]	495			495
Czech[2]	66865	455	125	66285
Denmark[3]	62081			62081
Estonia	22421	2425	2800	17196
Finland	18032	5616	4357	8059
France	224827	54447	41017	129363
Germany				
Greece				
Hungary	24390	12951	10980	459
Ireland	9369	4179	3874	1316
Italy	117241	35987	67939	13315
Latvia	13463	5844	4219	3400
Lithuania	45464	24061	19550	1853
Luxembourg	704	395	309	0
Malta[4]	582	27	15	540
Netherland	64144	22267	16557	25320
Poland	73741	22711	19065	31965
Portugal	11422	1625	2615	7182
Romania	32783			32783
Slovakia	12252	5586	4586	2080
Slovenia[5]	821			821
Spain	181636			181636
Sweden	29578	15654	11674	2250
Turkey	9494	1904	1394	6196
UK	129548	1134	427	127987
Total	1186962	232498	225297	729167

[1] Very limited data for Cyprus which could not be broken down by gender.

[2] For Czech Republic, breakdown by gender was only available for a small number of residential services.

[3] Denmark, Spain and Romania no breakdown was available by gender.

[4] For Malta, breakdown by gender was only available for a small number of residential services.

[5] Very limited data for Slovenia which could not be broken down by gender.

Disability of residents

Table 8 shows the number of residential places provided for each main disability group according to official sources in each country.

Table 8 Disability of residents as classified by official sources

Country	Places	ID	MH	PSD	Mixed	Not classified or other
Austria						
Belgium	25750	13345	1477	550		10378
Bulgaria	13269	8482	1376	2078		1333
Cyprus	495					495
Czech	66865	16047	1122	1399	2213	46084
Denmark	62081					62081
Estonia	22421	1945	940	2009	334	17193
Finland	18032	12532	5500			0
France	224827	107188	34239	28777	14352	40271
Germany						
Greece						
Hungary	24390		5351		19038	1
Ireland	9369	8073		515		781
Italy	117241		32806	3258	72906	8271
Latvia	13463	2405	1642	1128	3299	4989
Lithuania	45464		2814	805	11495	30350
Luxembourg	704					704
Malta	642	199	314		10	119
Netherland	64144					64144
Poland	73741	17294		4047	2586	49814
Portugal	11422	360	2216		8114	732
Romania	32783	7040	7563	1120	1457	15603
Slovakia	12252			1093	5585	5574
Slovenia	821					821
Spain	181636	20376	2948	3514	1822	152976
Sweden	29578					29578
Turkey	9494	2805	86	367	3	6233
UK	129548	46877	23205	8606	18330	32530
Total	1190432	264968	123599	59266	161544	581055

For half the places reported, the disability group was not known, making cross-national comparisons very difficult. The largest client group reported was people with intellectual disabilities, for whom approximately 265000 places were provided. The next largest category was the nearly 162000 places in establishments which mixed different client groups (for example people with mental health problems and people with intellectual disabilities).

Staffing

Where available in each country, data on staffing was collected. In particular data was collected on the number of staff in services, the nature of staff posts and the training direct care staff had. Data on staffing was unavailable or too limited to be useful for most countries. However for Belgium, France, Italy, Latvia, Lithuania, Luxembourg and the Netherlands data was available on staffing numbers with all but the Netherlands able to provide a breakdown of the type of staff employed. Table 9 illustrates the staffing information for these countries.

Table 9 Number and type of staff employed

Country	Total	Care	Day	Care/ Day	Managers/ admin	Clinical	Other	Not specified
Belgium	21842	152	5927	7985	1330	2509	3939	0
France	128420	18734	65138		15934		28614	0
Italy	114296	41726	9410		6824	33260	23076	0
Latvia	6977	1382	1501		360	560	3174	0
Lithuania	10780	3237	1787		250	1146	4360	0
Luxembourg	561			325	17	123	95	1
Netherlands	85935							85935

As already noted, it was not possible to distinguish between day and residential places in some of the French service types and therefore the number of day staff (which includes educators) is very high for France.

Information on training levels for staff was only really available for Belgium and Netherlands, with data on level of training available on 9047 care and day staff in Belgium and 67097 care and day staff in Netherlands. Of these 49% of care/day staff in Belgium and 69% in Netherlands had a higher or degree level qualification.

Estimating the level of residential and institutional care

It is evident from the preceding presentation that national sources of data on the number of people in residential services provide a very limited basis on which to plan for the transformation of services required. However, some of the data provided were more complete than others and there are also other sources of data which can be used to adjust the figures supplied to provide reasonable estimates. Estimates were calculated by the project team so that the same methods were used for each estimation depending on the nature of data available.

Table 10 uses these alternative sources in conjunction with the template data and country reports to provide the best estimates possible of the number of people in residential services in the countries studied and the number of people living in residential institutions of more than 30 places. Since the number of places is influenced by the population served, the table also presents the rate of provision per 100,000 total population as recorded in 2006 in United Nations statistics.

As can be seen by the notes under the table, different methods had to be used to estimate numbers. Where it was felt that data on number of people was as accurate as it was possible to be from official data sources, this figure was used to calculate the rates of residential care. For other countries, number of places/people in residential care had to be estimated from other sources. For Germany, for example, data was available from a previous EU funded project on intellectual disability (the Intellectual Disability Research Network[15]), from more unofficial sources as outlined in the Country Report on Germany and from academic contacts in Germany. In Finland it was necessary to use a mixture of the information available on intellectual disability from the template from this study, plus data from the Included In Society project in 2003[16] on mental health and physical disability. In terms of estimating rates of institutionalisation (ie. places in homes over 30 places), where data on size was available for at least 60% of the places identified, this data was extrapolated to 100%. For Spain, France, Slovakia, Sweden and Ireland, data on number of places in services of greater than 30 places was estimate from what was known about the typical size of each service type. For Latvia the calculations had to be done using the number of institutions and typical size of institutions as provided in the service descriptions. For the Netherlands, data provided in the template was mainly for mental health and physical disability and so data from the working papers of IDRESNET were used to estimate number of people with intellectual disabilities. The official data represented in the template only differentiated services over 12 places and data was not provided on service types which were noted in the service descriptions as providing many more than 30 places. Other sources of data from research and indeed the country report on the Netherlands, indicated that many services over 12 places still exist and that at least some of those identified as providing services of less than 12 places were in fact wards or houses in a much larger campus setting.

Overall, these estimates must be regarded as a starting point for improving the information individual countries have about services they provide for disabled people. As each country develops its approach to shifting from institutional services to services in the community, more accurate data will be generated.

Table 10 Estimated number of places and rates of residential care and institutionalisation

Country	Total places	Rate of residential care per 100,000 population	Total places in services > 30 places	Rate of institutional care per 100,000 population
Estonia	9050	673	7243	539
Latvia[b]	12295	536	12275	535
Lithuania	15114	444	14924	439
Spain[a]	181636	415	156004	357
Slovakia[a]	19043	353	18755	348
Czech Republic[d]	35004	341	30987	302
Slovenia[g]	5510	275	5414	270
Italy[h]	178830	304	153798	262
Netherlands[f]	115844	709	40924	251
France[a j]	203700	324	155522	247
Germany [c]	237682	288	190146	231
Hungary	24390	242	22546	224
Poland[a]	73741	193	73741	193
Belgium	23294	222	18130	172
Bulgaria [h]	12921	167	12561	163
Finland [e h]	23903	455	8500	162
Malta[h]	582	144	555	137
Romania	29828	138	29482	136
Ireland[a]	9001	214	5123	122
United Kingdom[h]	129548	215	66342	110
Portugal	11422	108	6995	66
Luxembourg	704	153	294	64
Turkey	9411	13	9301	13
Sweden[a]	27328	302	0	0
Austria				
Cyprus	495			
Denmark[i]	62070	1144		
Greece				

Notes:

[a] Number of places over 30 estimated from typical size

[b] Estimated from number of institutions and typical size

[c] Estimated from data available in several regions on ID - 70-80% of people with ID in homes over 30 places - IDRESNET plus Country report plus expert advice; refers to disabled people in residential facilities funded under the Integration Assistance Act. Not included are old people in nursing care homes

[d] Estimated from size of service, and IiS data on size of institutions for children.

[e] Estimated using IiS data plus data provided on ID.

[f] Template data only for MH and PD; IDRESNET figures for ID places - total places and places over 30. From template used figure for over 12 places as representing over 30 places given that data not entered for some of services which service descriptions said were over 30 as typical size - an underestimate as many of the places below 12 are likely to be wards or campus settings.

[g] Estimated using average size from IiS data plus number of services provided in commentary

[h] Number of places over 30 extrapolated from given data if more than 60% of places had size data available

[i] May include some older people without pre-existing disabilities.

[j] Includes some people who are not residing in the service but attending on a day basis only.

4. Service development in England, Germany and Italy

Introduction

This section of the report looks at service development in three European countries. It gives a brief overview of the way residential services for disabled people have developed and then comments on the roles of different actors on the process of change. Finally, this section identifies the main issues arising in pursing the transition from institutional to community care.

The three countries selected as case studies are all mature democracies with well-developed non-governmental organisations and networks in civil society, able to give voice on behalf of disabled people and to influence the legislative and policy process. All three countries have a legacy of institutional care for disabled people and are moving along the road from institutional care to services in the community. Germany and Italy are both what is called 'conservative' welfare-state types[10], characterised by the extensive use of social insurance schemes to manage eligibility for and access to services. England is an example of the 'liberal' type, in which the role of the state is restricted to providing a 'safety-net' and the provision of services is seen as a marketplace.

Detailed descriptions of the service system in each country are provided in Volume 3 of this report. It is important to note that Germany and Italy both have very strong regional structures, leading to substantial variation in policy and practice. Thus in the analysis presented below, the impact of the laws and policies described varies in different regions. The issue of variable implementation across territories also arises in England at the level of the local authority.

Sequence and process of service development

Germany

In the early 20th century, Germany possessed well developed institutional provision, particularly for people with intellectual disabilities, mainly provided by church-based groups organised into large networks. The state role was primarily as funder of services. The policy aim was to relieve local government bodies of the costs building institutions and providing care, so funding was organised on a regional basis. Although institutions espoused therapeutic aims, these were gradually subverted by eugenic ideas, culminating in the murder of about 200,000 disabled people by the Nazis[17].

After the Second World War developments in East and West Germany followed different patterns. In the German Democratic Republic, disability concepts and policies followed the Soviet concept of 'defectology'. Services for children and adults with more severe intellectual disabilities were either run as a part of the statutory health sector, led by medical doctors, usually psychiatrists, or by Protestant institutions that had existed before the war. The conditions in these institutions were similar to those in other communist countries of the time, and materially very poor. Post-war development in West Germany was modelled on arrangements before the war. The division of state funding competencies between a local and a centralized level was re-established. In order to relieve the local structures, intellectually disabled people were accommodated in large centralized and centrally-financed institutions. This created a mechanism led to specific arrangements that financially favour institutionalisation from the perspective of the local authorities and impede the implementation of integrative approaches within the community. Types of services under the 'new paradigm' such as family support services and supported living for adults with intellectual disabilities fall to local budgets, while residential services (community homes, institutions, etc.) are in the budgets of a central state authority.

At the beginning of the 1970s, in common with some other countries, institutional care came under criticism, particularly in mental health. A national inquiry in 1971 recommended immediate improvement of the conditions in mental hospitals and devised four principles to guide far-reaching structural reform:

- care should be delivered close to the community
- it should be needs-led and comprehensive
- it should be coordinated in catchment areas
- there should be equal access to care and quality of care.

Psychiatric hospitals remained the basis for care, whilst at the same time the proposals gave rise to the development of acute psychiatric wards or units attached to general hospitals. A further review in 1988 set the target of building comprehensive community services. The central aim was to provide care in the community for people with chronic mental illness according to their needs and to ensure long-term patients could be discharged. New services were created in all regions of the country. However, there are still many long-term patients (20,000) residing in psychiatric hospitals who have not been discharged to the community. The construction of a comprehensive system has been constrained by problems such as the co-ordination of activities, since many of the community services are run by charitable organisations and other non-statutory agencies (often with their own vested interests). Nevertheless a substantial network of community services has been developed. Psychiatric hospitals have continued and have been subject to attempts to raise standards through binding regulations on minimum staffing levels.

In intellectual disability, a strong parents' organisation (Lebenshilfe für geistig Behinderte) became both an important lobbying organization and an important service provider. Lebenshilfe was critical of the institutional system and campaigned for an alternative to the traditional model of care in large institutions. The Social Assistance Act of 1962 (Bundessozialhilfegesetz)[18] provided a financial basis for extensive investment in local services for people with intellectual disabilities, including residential homes. These co-exist with large institutions but still provide a minority of residential places for people with intellectual disabilities. Approximately 120,000 persons with intellectual disabilities live in residential facilities; 16,000 live in community homes, 60,000 in institutions, a further estimated 20,000 in psychiatric facilities or large institutions with a medical orientation. The percentage of intellectually disabled adults who live neither in their families of origin nor in facilities but live independently and use non-residential services is not recorded (but the difference of approximately 10,000 persons that can be calculated from the above figures might provide a realistic indication).

From the beginning of the 1980s a disability rights movement developed in Germany which has promoted support to enable people to live as they wish in the community.

This movement has defined the question of the amount and kind of assistance given to disabled people as a matter of quality and rights, rather than administrative or professional judgement. This, combined with continuing criticism of institutional care and with increasing cost pressures in the funding system, led to creation of a mandatory, universal social assistance programme for long-term care in 1994. This programme has achieved many of its stated policy goals: shifting the financial burden of long-term care from the states and municipalities to federal level; expanding home and community-based services; lessening dependence upon means-tested welfare; and increasing support of informal care givers. It has also exposed some difficulties for social-welfare administrations and for service providers of reconfiguring their work to adopt individualised, person-centred approaches.

Italy

The main area of service development in Italy has been the reform of mental health services. In 1978, Law 180 legislated for the closure of psychiatric hospitals, a network of new mental health facilities on a regional basis, with the person at the centre of care. The prohibition of new admissions led to a decrease in hospital beds from 60,000 in 1978 to 2,500 in 1998. New mental health structures were created including outpatient clinics, new departments in general hospitals, mental health centres, and residential settings designed to provide differentiated kinds of treatment aimed at reducing the need for hospitalisation, and reducing the duration of time spent in treatment. The last 15,000 patients living in the 57 mental hospitals are officially resettled to residential facilities and family groups (1992). However, some hospitals remain partially open and district-based services have been slow to develop. Three general patterns seem to be emerging regarding the pace and spread of reforms, although there has been increased momentum in recent years:

- In small/medium sized towns in the north and centre – full implementation of reforms
- In large urban areas – new community-based services, but no running down of existing facilities: diversification of services, little co-ordination
- In the south – no change, little reform[19].

The administrative decentralisation of Italy favoured local initiatives but provided an obstacle to the implementation of the new law – at local and regional level, partly due to the politicised situation, it was difficult to agree national standards. The wide disparities in resources, levels of institutional provision, professional staffing, degrees of dependency on charity or private initiatives, political cultures between North to Centre to South and the islands of Sicily and Sardinia make it hard to judge the full impact. For example of the 95 provinces in Italy, only 52 were directly responsible in 1979 for managing all psychiatric services in their area – the others depended on varying degrees on contracting out of services to, in particular, Church-sponsored psychiatric hospitals[19]. Most of the provinces dependent upon the private sector are concentrated in the South and Lazio, the region around Roma.

The trend of decline in hospital numbers began before 1978; the Law then accelerated the fall. By 1983 there were about 43,000 beds (76 per 100,000) from a peak in 20 years earlier of 98,000. With a decline in public beds there has not been a corresponding rise in private beds, which have declined from 26,000 in 1972. Private beds continue to play a role, especially in the South and Lazio region.

The new in-patient facilities were small 15-bedded units in general hospitals. As of 1984 there were 236 units with just over 3000 beds (5.5/100,000 population). There was a great deal of variation in the level of provision across different regions ranging from high rates in the Veneto region (11 beds per 100,000) to Lazio (1.4:100,000). This might conceal either poor implementation or general scarcity of facilities (as in Roma) or a well-developed network of community services that were working well and required little in-patient facilities (Emilia–Romagna).

Residential facilities largely replaced mental hospitals for long-term residential care of people with mental health problems. These include boarding houses, halfway houses, unsupervised hostels or apartments and intermediate facilities. Referrals are made by local departments of mental health that pay for residential care. There is only limited information about the characteristics of these facilities, the environment and staff[20]. These services usually have a home-like atmosphere, but restrict the behaviour of clients. Length of stay is indefinite and turnover is low. In 2000, there were 1,370 services with four or more beds in Italy, with 117,138 residents at a ratio of 29 per 100,000 population. Half had been set up between 1997-2000 and large proportions were privately owned (although all expenses were covered by the National Health Service). The amount of residential provision varied tenfold between the regions. Most have 24 hour staffing, although a substantial proportion of staff had no specific mental health training. Services located in the northern regions tend to be less restrictive and often cluster style. They are not supposed to have more than 20 beds, although 16 (5.7%) did and one had 60 beds. Private facilities had a higher number of beds than state –provided services (ratios 14.9:11.6).

A random sample of 265 psychiatric residential services[21] found that most were independent buildings located in urban or suburban areas. The median number of residents was 10. Those with more than 20 beds have a higher rate of drop-outs and absconding. Usually there are two residents to a bedroom with an average of one bathroom for 2.5 residents. Most establishments have two or more common rooms, although less than half had a private room where residents could meet visitors. Only two thirds prepare all meals inside the facility, the remainder use a catering service. More than half had architectural barriers that made it difficult for physically disabled residents. Most facilities have a garden and are located within walking distance of shopping centres or recreational facilities, though in 30% of services residents were not allowed out alone. 75% have 24 hour staff coverage.

England

The general pattern of development of English residential institutions from the late 17th Century was of the growth of general institutions (‘workhouses’) for all homeless and destitute people; increasing specialisation within these institutions followed by the development of specialised institutions such as hospitals for the sick and asylums for people with mental health problems or intellectual disabilities[22]; a shift from therapeutic to custodial regimes in line with emerging eugenic ideology[23]; criticism of institutional care and the development of alternatives[6]. Throughout this period it needs to be remembered that families provided most care and support for many disabled people; in general, services have only ever provided a fall-back when families were unable to cope themselves.

By the Second World War, large residential institutions, often built in the 19th Century, were the typical form of provision for people with intellectual disabilities, people with mental health problems, for orphans and for the homeless. Institutions also existed for people with physical or sensory disabilities, though often these people ended up in hospitals or other institutions.

Following the Second World War, greater interest in the effects of institutional care led to a growing critique of its use. An official report recommended moving from large institutional orphanages for children to small 'substitute homes' of no more than 12 places in 1946; A Nuffield Foundation report in 1947 recommended homes for old people of 30-25 places instead of 200-1500 places. These changing ideas were not yet applied to people with intellectual disabilities or people with mental health problems. At the creation of the National Health Service in 1948, it was decided to transfer institutions for these groups to the NHS as hospitals, since they were already usually under the direction of medical personnel. The institutions continued in this new guise.

The critique of institutions did however begin to bear on NHS services too. A Royal Commission report in 1957[24] recommended the development of more services provided outside hospital by local government for people with less serious problems. The peak population of mental health hospitals was reached in 1955 at 150,000 people, after which the numbers gradually declined, partly as a result of advances in treatment and partly because of this shift in policy in favour of more care outside hospital. Alternatives to institutional care began to be developed in intellectual disability too[25,26].

The major turning-point in policy in respect of residential services for people with intellectual disabilities or people with mental health problems came in the late 1960s with a series of scandals in hospitals[29-33]. These involved ill-treatment, outdated and neglectful methods of nursing care, professional incompetence or inadequacy, administrative irregularities, overcrowding, under-staffing, poor facilities, management failure, failure to investigate complaints and victimisation of staff who did complain[6]. Although initially represented by politicians as exceptions, a national survey of institutions for people with intellectual disabilities showed that similar conditions were in fact the norm[27]. The effect was to raise to a high priority in the health ministry the quality of residential services for people with intellectual disabilities and people with mental health problems for many years.

New government policies on intellectual disability services in 1971[28] and on mental health services in 1975[29] proposed (more clearly in intellectual disability than in mental health) a reduction in institutional places through the provision of more places in small residential homes provided outside hospitals. Thus the policies embodied the assumption that people could be divided into two groups: those who 'needed' hospital care and those who could be supported to live in small residential homes in the community. This boundary was immediately attacked as irrelevant by those who argued that everyone, given sufficient support, could live in ordinary housing among the general population[30]. Within a decade, models of such services were in operation[31-33] in intellectual disabilities, and the principle of community-based residential services for everyone was becoming accepted in policy[34,35]. These models were given added impetus through a national demonstration project [43-47].

In the 1980s and 1990s, substantial progress was made in deinstitutionalisation and community living for people with intellectual disabilities and people with mental health problems, without national government ever clearly articulating the goal of institutional closure. The lack of a clearly articulated policy goal, and the absence of a firm legal or constitutional basis for non-institutional services, has led to some trans-institutionalisation (with some new services, particularly in the for-profit and government sectors, being larger than private homes and institutional in nature). In intellectual disability, where the best official information exists, there were over 58000 places in residential homes for adults in 2005 (average 8 places), compared with approximately 2500 places in institutions[36,37]. As the main part of this transition has been achieved, government policy has finally adopted the principle of services in the community[38].

The replacement of institutions with services in the community in England has largely been a professionally led development[6]. However, beginning in the 1980s, the independent living movement, led by people with physical or sensory disabilities, developed an alternative model of community services based not on buildings at all but on the provision of personal assistance. This movement has been successful at obtaining legislative change to create mechanisms by which direct payments can be made in lieu of services, so that people made and control their own arrangements[39]. Take-up of these arrangements has been low, not least to administrative obstacles[40], but government has continued to promote individualised funding and services as the desired future model of care for everyone with disabilities[41,42].

Roles of different actors in the process of service development

National, regional and local government

In all three countries, national government takes responsibility for setting the legislative framework, the overall direction of policy and the overall funding arrangements for health and social care. Germany and Italy both have strong systems of regional government. In Germany, the primary responsibility for planning health and social care services for disabled people rests with the regions and municipalities, with national government taking a only a limited role. In Italy, regional governments have primary responsibility in respect of health services, with provinces and local authorities having responsibility for social care. There has been a general process of decentralisation to subordinate tiers of government in recent years. In both countries this process limits the involvement and responsibility of national government for the condition of disabled people.

England does not have regional government and responsibility for the provision of health care and of social security benefits lies with national government; the provision of housing (including some housing benefits), education and social services are the responsibility of local government. Most English health care is provided by the state-run National Health Service (NHS) which is tax funded and free at the point of delivery. A fee-charging private sector also exists alongside the NHS. When the NHS was formed in 1948 it took over existing hospitals and institutions from local authorities and independent organisations, including residential institutions for disabled people.

Unlike health care, social services in England are not free but are means-tested. Local government councils themselves set thresholds (eligibility criteria) for those people to whom they will provide some funding. The fact that health services are free but social services are not also creates perverse incentives for people using services that could be provided either by health or by social services agencies. Since local government is substantially funded by national government, there are opportunities for national government to influence the form and amount of local services if it wishes.

The potential implication of devolving not only the responsibility for ensuring *provision* of services but also aspects of *policy* is that different regions or local authorities might decide on different priorities, set different thresholds or criteria and provide different models of service. This can lead to what has been called in England the 'postcode lottery' – in which the kind of services a person receives (sometimes whether they even receive services at all) depends not on their needs but on where they live.

This makes the national government role of defining standard or basic entitlements or rights particularly important to ensure that the human rights of disabled people are properly met. All three countries show examples of national action in this area. For example, in Germany in 1994 the constitution or Basic Law (Grundgesetz)[43] was amended, including the statement that no-one may be disadvantaged by reason of their disability. An Equal Opportunities for People with Disabilities Act (Bundesgleichstellungsgesetz)[44] was passed in 2002, as was a Caretaking Act (Betreuungsgesetz)[45] designed to provide for substitute decision-making on behalf of people deemed unable to make decisions unaided. In Italy, Law 180 of 1978[46] abolished psychiatric hospitals. Law 104 of 1992[47] promoted the civil rights of people with intellectual disabilities and their integration in society; Law 162 of 1998[48] extended the types of services available to people with severe disabilities; Law 328 of 2000[49] aimed to integrate service provision for disabled people. In England, the Disability Discrimination Acts[50,51] prohibit some kinds of discrimination against disabled people. The Mental Capacity Act[52] provides for substitute decision-making for adults who are deemed unable to make decisions unaided. The Care Standards Act[53] prescribes minimum standards and the regulation and inspection of some kinds of services for disabled people.

Decentralisation of decision-making also implies that it is important for national governments to collate information about the living circumstances of disabled people in order to monitor progress towards meeting their rights – not least in the transfer from institutional care to services in the community. Thus the findings of the first part of this study are particularly relevant in states where the rhetoric of decentralisation and subsidiarity is important (subsidiarity is "the principle that a central authority should have a subsidiary function, performing only those tasks which cannot be performed at a more local level" *Oxford English Dictionary*). Although the planning and provision of services may be performed at a local or regional level, the task of ensuring harmonised application of principles and criteria requires national monitoring.

Similarly, there is evidence in all three countries that the management of the financial consequences of making the transition from institutions to services in the community requires national or regional involvement. Local municipal authorities may not be able to finance nor coordinate the finance for the whole process. In Sweden and Britain for example, national and regional authorities played a leading role until quite late in the transition process, when transfer of leadership to local government took place[6].

Non-governmental organisations

Non-governmental organisations played an important role in the development of services for disabled people in each of these countries. Religious, voluntary and self-help organisations were important in providing services before the state played a significant role.

In England, the provision of residential services for people with mental health problems and people with intellectual disabilities was substantially taken over by the state during the 19th and 20th centuries[22]. Residential services for people with physical or sensory disabilities continued to be mainly provided by non-governmental organisations, though many people with physical or sensory disabilities needing residential care were placed in long-stay wards of general or geriatric hospitals[54]. During the 1980s, the national government set out to achieve greater efficiency in the provision of these services (and also the much larger number of residential services for older people) through the creation of a 'mixed economy of welfare'. This involved (i) separating responsibility for planning and financing services ('purchasing') from running services ('providing') and (ii) making much more use of not-for-profit and for-profit organisations to provide services. These changes coincided with the main phase of closing large long-stay hospitals for people with intellectual disabilities and so have been associated with the adoption of housing-based residential models, particularly for this group. By 2005, over 90% of residential homes for adults aged under 65 registered by the Commission for Social Care Inspection in England were provided by not-for-profit and for-profit organisations[36].

Thus the landscape of service provision in England is currently that government agencies (particularly local governments) select and fund places in residential care, the great majority of which are provided by independent agencies. These agencies may be large national or regional organisations, but they may also be individual homes set up by interested persons. They are supposed to meet national minimum standards (though this is not yet achieved) and there is great variety of amount and quality of provision.

Italian services for disabled people are also provided by non-governmental organisations as well as government agencies. For example, just over half of the residential care services provided for people with mental health problems in Italy are provided by the National Health Service; the remainder being provided by voluntary organisations, private (for-profit) organisations or a mixture of the two[55]. The non-governmental service providers are mainly not-for-profit organisations, including user and parent associations. These organisation must be accredited on the basis of regional rules stating the requirements needed in terms of architectural features, staff qualification, programmes and local needs for services (waiting lists).

The German situation is different from that in England or Italy. Here too there is a strong tradition of service provision by non-governmental organisations. The pattern of residential care was predominantly institutional, and the costs of building institutions was so great that government shifted responsibility for this from local to regional authorities. Provision of services became dominated by a relatively small number of networks of organisations, the 'Freie Wohlfahrtspflege' (Diakonie, Caritas, the Workers' Welfare Association, the German Red Cross, the Independent Voluntary Welfare Association and the Jewish League of Free Welfare Services). These six umbrella groups achieved recognised legal autonomy from the State, and a status as preferred providers. The state is obliged to leave the provision of social services to the voluntary welfare organizations while it is obliged to meet the costs.

Public administration reforms from the 1990s onwards have focused on attempts to introduce market mechanisms that are to be linked with 'output-oriented forms of control'. The aim has been to establish a contract-based financing scheme based on compensation for services agreed in advance and including the description, scope and quality of services, in contrast to the conventional principle of 'cost recovery' (the retrospective compensation for all costs incurred). The reforms were also intended to achieve savings by creating an enhanced market and competitive situation by admitting new service providers from outside the 'Freie Wohlfahrtspflege'. However, these private providers still play only a minor role (for example, in NordRhein Westphalia they only provide about 4% of places).

Hence in Germany now the situation is characterized by relatively powerful third sector organizations with a strong tradition of institutional care. The state is moving to release itself from the role of mere funder to a more influential role in service development and design, but without starting with the necessary professional skills and personnel resources to do so.

Disabled people and their families

Disabled people and their families have been important in three major respects in these countries: (i) in service provision, (ii) service innovation and (iii) policy formulation. In respect of service provision, families have often supported their disabled member in the family home despite inadequate help and support from the community. They have also set up and run services – for example, Mencap is the largest provider of residential care homes for people with intellectual disabilities in England and Lebenshilfe provides a fifth of residential care homes in Germany[17]. Given limited control over the funding of services and the overall policy framework, such provision is itself sometimes not as innovative as it might be. The Italian approach generally holds the public sector fully responsible for services for people with disabilities. The disability representative associations fight more for a structured involvement in all the steps of the process, from legal framework and provisions to quality assessment, than for directly running services.

Disabled people and their families have played a leading role in recent years in developing new types of service. Probably the best example of this has been the growth of independent living for people with physical disabilities, which is promoted and led by disabled people[56] and now occupies a prominent position in European policy action through the European Network for Independent Living. Coupled with this campaigning role has been involvement in policy formulation, with governments beginning to require the inclusion of disabled people on relevant bodies (for example the creation of Equality 2025 in England as an advisory body to "bring the voices of disabled people into the heart of policymaking"[57].

It is also important to note that families of disabled people have sometimes resisted the replacement of institutions with services in the community. Research studies in countries that have pursued deinstitutionalisation and community living has shown that family concerns before transition are, for a majority of families, replaced by support after transition[63-66].

Staff and staff organisations

Staff have played a key role in the transition from institutions to services in the community. For many disabled people living in institutions, their quality of life depends critically on the quality of support they get from staff. Recent research in services for people with severe and profound intellectual disabilities has shown that, after the individual's disability itself, the most important factor in determining aspects of quality of life is staff interaction and support[67-70].

Large institutions concentrate residents from a wide geographical area. When they are replaced with services in the community, it may not be practicable for institution staff to relocate to the communities in which new services exist. It is therefore important to develop appropriate strategies to help such staff find alternative employment[58]. Where staff do move from institutions to support people living in the community they face the challenge of new roles and particularly of more responsibility[59,60]. A common feature, therefore, of new service models is the provision of new forms of training for staff. There is a challenge in developing these new forms of training to ensure that they both provide staff with the understanding and skills necessary to undertake the tasks involved, but also ensure that staff have the correct values to work as personal assistants in an enabling role.

People living with support in the community use ordinary public services and facilities – sports centres, hospitals, family doctors, employment offices, police etc. Personnel in these situations need training about disability awareness, disability rights and their responsibilities in respect of supporting disabled people. Staff organisations and accrediting bodies have a key role in identifying this as a requirement for acceptable staff performance.

5. Economic implications of community-based and institutional residential services

Introduction

In most European countries and for many decades, large institutions have been the dominant form of provision for people with severe and chronic disabilities. Many factors played a part in the original decisions to choose this model of care. It was believed that grouping people together in large numbers with (at least some) qualified staff was the most effective way to contain or perhaps even 'cure' people. Logistically, it helped to have the (very scarce) skilled professionals concentrating their work in one location. Institutional care was the preferred choice of many families who found it difficult or dangerous or (very commonly) socially embarrassing to live with their disabled relatives. Many would anyway have acted in good faith, firmly believing that their disabled, sick relatives would enjoy a better quality of life in remote, secluded settings, away from the ridicule and victimisation of everyday life. In some countries, the institutions became useful as instruments of social control. Economic considerations undoubtedly played an important role too – if nothing else, warehousing large numbers of people in one place allowed providers to achieve economies of scale. Economies of this kind were also easier to achieve if 'care' was replaced by containment, and individualisation was subjugated beneath uniformity. The archetypal 'institution' is cheap to run.

Apparent economies of scale are, however, complicated by the question of what quality of service is being provided. It is vitally important to take account of cost and quality together, and to make sure that comparisons between care settings or arrangements are being made on a like-for-like basis in terms of the needs and other characteristics of the people who use services, and the costs and aspects of quality that are included.

Part of making this relatively sophisticated comparison is to take appropriate account of the needs and preferences of the people served. As explained later in this section, if community services have only been available to people with less severe disabilities, they will be less expensive than institutions. When services are developed in the community for people with more severe and complex needs, they are likely to be more expensive than the existing community services.

This means that it is important to consider everyone who needs services when planning the transition from institutional care to services in the community. Some people formerly cared for in institutions will be able to live independently with very little support; others will need constant help from staff to accomplish activities of daily living at home and in the community. The spectrum of services available will need to include options for people with widely differing needs for support. Individuals will also vary in their needs over time – sometimes needing more support, sometimes less. Some of this support might need to be in the form of respite or short break care, or for assessment and treatment in (general or psychiatric) hospital. Thus decision-makers have to plan for a system of services in the community that will meet everyone's needs.

System structures

Before looking at the factors that encourage or hinder moves away from institutional services it is important to understand the context in which this transition takes place. Decision-makers need a thorough understanding of the structure of service provision, the underlying financing arrangements, and the ways in which services are funded if they are to understand the likely successes and failures of different approaches aimed at promoting community-based care. The main dimensions with a bearing on the economic evidence and its potential influences on policy and practice are threefold:

- Patterns of service provision
- Financing arrangements
- Funding routes

Patterns of service provision

Most provision of support for disabled people comes from families, friends and neighbours - the unpaid, so-called ‘informal’ care sector. Much of this goes unrecognised and unsupported. The availability of informal care heavily influences the level and nature of need for ‘formal’ care for which, by definition, funding must be raised in order to employ staff. Policy frameworks sometimes give the impression that informal care is a ‘free’ input, when in reality there are often quite high burdens and opportunity costs falling on families, with the implication that future supply might not be as plentiful as today. Possible constraints on the future availability of family care are discussed on page 75 *et seq*.

The needs of disabled people may be related in part to their health, in part to their physical and cognitive abilities to carry out the activities of daily living, in part to their socially excluded and impoverished circumstances, and in part to the social contexts (including constraints) in which they live. Some needs therefore require health care, while others are more appropriately met by social care services, or agencies responsible for housing, or education providers, or perhaps the criminal justice system, or by bodies with other specialist functions. If they have the right skills and resources (including time), families and unpaid carers more generally can often meet all of these needs, particularly for people with less severe disabilities. But once responsibility shifts partly or wholly to formal services, often provided by the public sector – in part because needs are too complex or demanding or distressing for families, or because it is simply no longer appropriate for the family to play this role – it is probable that more than one agency will be involved. Different patterns of service provision have developed in different countries, influenced by national culture, financing arrangements, bureaucratic procedures, the availability of skilled staff and – to a degree, sometimes a very limited degree – the preferences of service users and families. And within a single country it is likely that the boundaries between different agencies and services will change over time in response to similar forces.

Table 11 gives an example of the tendency for disabled people - in this case, people with mental health needs - to use multiple services. The data come from a study of two large psychiatric hospitals in London that were identified for closure in the early 1980s and whose closure programmes took 8-10 years to complete[61]. Box 1 and Box 2 give brief descriptions of the early accommodation and service experiences of two of the people who moved out of one of those hospitals during that period.

Table 11 Service use and costs in the year after people left two London hospitals in late 1980s and early 1990s

Services used in the community	Individuals using each service[1] (%)
Accommodation and living expenses	100.0
Hospital out-patient services	25.9
Hospital in-patient services	14.8
Hospital day-patient services	22.9
LA social services day care	17.4
Voluntary organisation day care	15.2
Social club services	6.6
Education classes	4.5
Community psychiatry services	57.8
Chiropody	41.3
Nursing services	29.1
Psychology services	14.4
Occupational therapy	8.6
Drugs (depot injection)	14.3
Miscellaneous services[2]	18.6
Physiotherapy	2.4
General Practitioner	74.5
Dentist	25.3
Optician	19.9
Community Pharmacist	5.8
Field social work	23.6
Police and probation services	5.8
Client's travel	29.3
Volunteer inputs	1.7
Case review	9.9

Notes

1. Data available for those people for whom full service use data were collected (n=533)
2. Includes a number of services each used by only a few study members. Examples are finance officer, aids and adaptations, audiology, aromatherapy, employment officer, home help, job club and reminiscence group.

Problems can often develop in this multiple-need, multiple-provider context. Boundaries between services and agencies may not be clear or stable. Providers in the health, social care, housing and other sectors may have different underlying cultures (such as the tension between medical and social models of disability), different eligibility criteria (which could influence threshold levels for admission, for instance). In turn, this could encourage cost shifting and could increase the risk that gaps emerge between service systems, so that some needs or some individuals get missed altogether. Coordination is a fundamental requirement of community-based care systems.

Box 1 Della – establishing herself in the community

Della was one of the first residents to leave Friern (psychiatric) Hospital in north London under the programme to close the hospital and develop community care in the mid 1980s. She moved into a flat rented from the local authority with a friend (also a former inpatient at Friern), but as this involved Della sleeping permanently in the living room it was not an ideal arrangement.

During the year after leaving hospital, Della had regular contact with a social worker and a primary care physician and saw a psychiatrist in two occasions. This was a very low cost support package. Although she had no inpatient admissions within the first year she was soon re-admitted to Friern Hospital and stayed there for just over a year. Her second move to the community was to a residential unit with 24-hour staff cover. Although she was now getting a much higher level of staff support she was nevertheless re-admitted again to Friern Hospital and – once again – remained there for a year before she was transferred to another hospital and the researchers lost track of her.

Box 2 Freddie - moving from hospital to a high-staffed care home

Freddie left hospital quite late in the closure programme, moving to a residential care home in which six staff provided 24-hour cover. The home was owned by a housing association and managed by a consortium arrangement between the health authority and a voluntary organisation. Freddie was one of nine residents and was judged to have ‘medium’ care needs.

An occupational therapist made regular visits to all the residents and the six-monthly case-reviews involved a community psychiatrist and the primary care physician. Freddie also had regular contact with a social worker, and police officers were involved on several occasions when he caused a disturbance in the street.

The cost of this care package was relatively high due to several short admissions to a general hospital for psychiatric treatment. Each time he was admitted his place was kept open in the community home. This raised the cost of his care package as both placements had to be funded. However, it also meant that Freddie had a stable community placement that he knew and where the staff knew him, and this meant he would not become a long-stay hospital patient again.

The difficulties of coordination across agencies and budgets could be exacerbated if provision is spread across public, voluntary (non-profit, charitable) and private (for-profit, commercial) sectors. In some countries the state sector dominates provision, but across Europe there are many provider responsibilities sitting with the voluntary and private sectors, as well as the user advocacy, family support and campaigning activities that have traditionally been dominated by civil society. These responsibilities have developed in response to a number of stimuli, and have a number of implications[62]. They can develop, indeed thrive, in systems where the state (centrally, regionally or locally) retains full strategic responsibility for setting the policy, legal and financial frameworks for provision, access, allocation and quality assurance, as in Italy and England. There is much less central policy control or influence in Germany. In all three countries, however, non-state providers have taken on important roles as long-stay institutions have closed, offering a range of accommodation and other services in the community, often heavily reliant on state funding. For some discussion of the roles of non-state services see the country reports from this project and, for example, work by Crepet[63] and de Girolamo and Cozza[64] on the situation in Italy; and Lelliott *et al*[65] and Knapp *et al*[66] on England and Wales.

The multifarious contributions of the non-state sectors need to be recognised by policy makers, and factored into their coordinated community-focused plans for supporting disabled people. A complication is that non-state bodies operate within different legal frameworks, often pursue different motivations, and respond to different incentives. In consequence, state and non-state sectors might have different user mixes, costs, quality of care and perhaps even user outcomes. The commissioning and coordination of community care will therefore need to factor in possibly very marked differences in approach (see page 83).

Financing arrangements

There are a number of approaches to the financing of health and social care, usually grouped into four types (for general discussion of these, see Mossialos *et al*[67] on health care financing in Europe; Wittenberg *et al*[68] on financing options for long-term care for older people; and Knapp & McDaid[69] on mental health systems in Europe.) The main types are:

- out-of-pocket payments by service users or families ('user charges')
- voluntary insurance, sometimes called private insurance
- tax-based support, funded from direct and/or indirect taxes (national, regional or local), and with services provided on the basis of need
- social insurance, funded through hypothecated contributions linked to employment, with services again provided on the basis of need.

Most care systems combine a number of financing approaches, for example having some user charges within a system that is primarily financed out of tax revenue. One issue that can arise, therefore, is whether a combination of sources of finance for a particular service or sector creates a barrier to change, or whether differences in financing arrangement between institutional and community systems, or between (say) health, social care and housing systems is similarly obstructive – or indeed facilitative. An example would be current tension in England, where health care is free at the point of use while social care is means-tested, which could create a difficulty if someone is to be discharged from hospital to a care home and is then liable for user fees.

The four main financing approaches differ in various ways, including the balance between private and public (societal) funding, the nature and extent of risk pooling, the nature and extent of government intervention, and the contribution (if any) to redistributive policies. The last of these is particularly pertinent, given that most disabled people are in low-income groups, so that reliance on user charges could be punitive and disadvantaging. Introducing or extending the use of user charges can very quickly lead to under-utilisation of needed services[70], with unwanted – perhaps dreadful – consequences for other service systems, quality of life and indeed for mortality (eg Soumerai *et al*[71] in the USA). A common theme across many European (and other OECD) countries is to try to shift the balance of financing a little away from collective responsibility (through taxes or social insurance) to individual and family responsibility (out-of-pocket payments or voluntary insurance). Out-of-pocket payments have been introduced for psychiatric services in Poland as part of a broader economic transition policy[72]. The shifting balance from public to private responsibility is perhaps most evident in long-term care for older people, given the considerable future challenges of supporting rapidly ageing populations.

Another common theme, although one that is not so widespread across Europe, is growing interest in self-directed or consumer-directed care systems[73]. The long-term care financing arrangements in Germany are of this kind, and there have been noticeable developments in Sweden, the Netherlands and England. The primary aim is to give more independence and choice to disabled people, and thereby give them greater control over their lives.

Another development in Germany – the long-term care social insurance system for older people – offers another illustration of the influence of financial incentives[74,75]. The system was introduced in 1994, funded by employers and employee contributions: it now covers around 90% of the population, with care for the reminder continuing to be funded through public assistance. Alongside population pressures and rising costs the system has some perverse incentives. Assessment for one of three levels of assistance (need for considerable, intensive and very intensive care) happens at entry to the system and there is no formal requirement for re-assessment unless the older person, their relatives or the institution in which they live asks for it. Rehabilitation is paid for through the health care insurance budget, with perhaps some interest in shifting costs to the long-term care insurance scheme than paying out high provider costs, which creates a disincentive to fund rehabilitation schemes and a preference for higher long-term care rates (‘transfers’). Together, these mechanisms make it unusual for people to move from higher to lower care levels even if their condition improves.

These approaches to financing are considered below when looking at the evidence.

Funding routes

How do the finances raised from taxation, social or voluntary insurance, or out-of-pocket payments by users or families reach the providers of services? Funding is the generic term that can be used to describe the many different routes by which money reaches services. It embodies various allocation mechanisms, with various incentive structures attached.

In some systems, finances raised centrally are allocated directly to providers (such as state-sector hospitals) through grant mechanisms, perhaps with performance-related incentives intended to persuade providers to deliver more or less of a particular service. Indeed, performance targets overlaid on funding links have become increasingly influential in some systems, such as the health and social care structures of England.

Alternatively, the decision may be taken to allocate centrally raised revenue to commissioners (i.e. to ‘demand-side’ bodies rather than ‘supply-side’). The allocation can for example be on a capitation basis, weighted for need, and/or to compensate for historical patterns of provision or variations in input prices, and perhaps also with some performance conditions attached. A variant of this model is to employ some kind of health-related (or diagnosis-related) group arrangement, or its equivalent in other service systems, which pre-specifies the price that the commissioner will pay to the provider for an individual patient or user with a particular diagnosis or set of needs.

Commissioners will then be charged with the responsibility of assessing population and individual needs, identifying potential providers of services that can meet those needs, and then entering into some kind of contractual relationship with them. Services can be purchased on behalf of users from providers using any of quite a range of contract types, such as block, spot or cost-and-volume contracts. These can come with or without contingencies for externally generated difficulties such as general price inflation; and also with or without conditions attached to the quality of care or the outcomes to be achieved. Length of contract is another relevant consideration, given providers’ needs to have sufficient security to be able to invest in buildings and staff development, and given commissioners’ needs for flexibility. Contracts could be agreed within hierarchical systems of care or in more market-orientated structures, obviously with a range of different operational and perhaps performance implications. Another consideration – linking back to the discussion of the often complex patterns of provision for disabled people – is whether some form of *joint* commissioning is needed, say between health, social care or housing bodies.

A third option is to introduce consumer-directed care, with individual service users or their carers given responsibility for purchasing services to meet their own needs, either through direct allocation of funds or through individualised commissioning arrangements such as brokerage.

One final consideration to mention at this stage is that some public funding could reach disabled people through their entitlements to social security (welfare) benefits or allowances. These might be prompted by their assessed disability, to compensate for necessarily higher costs of (say) transport or heating their accommodation; or they might be paid to compensate for low income because of the high rate of unemployment experienced by disabled people. In some countries there might be funding transfers paid to the carers of disabled people.

If every service and support that an individual receives was provided by the same organisation, the funding challenge could be managed by funding everything from a single budget. Even in this situation, there would be likely to be some services funded by other routes. In practice, the variety of options for funding routes is large. Each of these different funding routes is characterised by, or creates a set of incentives, whether explicitly or implicitly. Funds almost always reach providers with various conditions attached. Some are more susceptible to political interference. Some give more power of influence to individual service users. Some are short-term and others long-term arrangements. And, to complicate matters, the tendency for many people with disabilities living in the community to use a range of services from a number of different providers will mean that there are multiple incentive structures at play, with perhaps some of them pulling in one direction and some in another. The challenge of coordination is therefore all the greater because of the complexity of marrying up different funding arrangements and the organisational behaviours they encourage or delimit.

Overview of barriers and facilitators

Set against this background of multifarious patterns of provision, variable arrangements for health and social care financing, and the sometimes complex routes that funds can take before linking the two, it is possible to identify the barriers to and facilitators of change in the balance of care. The sections that follow discuss each of these barriers and facilitators by drawing on evidence from the three study countries (England, Germany, Italy) and from across the range of service user or need groups (mental health service users, people with intellectual disability, people with physical disability or sensory impairment, disabled children, and older people with age-related needs). One point to emphasise at the outset is that some factors can be both barriers and facilitators, depending upon the context within which they arise.

At the most fundamental level, the existence of a broad *policy framework* is clearly likely to be a major influencing factor. Surprisingly, many countries in Europe still do not have a formal policy covering some service user groups. For example, the World Health Organisation has pointed to the number of countries without a formal mental health policy. A more specific plan for the closure of an institution is similarly likely to be a major facilitator. Countries that seek to alter the balance of care without first drawing up appropriate plans that span relevant domains and that stretch sufficiently far into the future are storing up a number of problems. The facilitating qualities of national or regional policies, and also of specifics plans concerning the balance of care, and, yet more specifically, the closure of institutions are considered on page 52 *et seq*. One very important ingredient for success is having a (realistic) vision for what is can be achieved in community-based systems of care; many policies aimed at closing institutions have embodied rather unambitious plans for individual service users.

In an ideal world, those policies and plans would take full cognisance of the preferences of individual service users, their families (in so far as a family perspective is relevant) and of the wider society (again in so far as that is relevant). But those preferences, or at least those sought and/or expressed, could be both barriers and facilitators. For example, studies have shown that many people living in long-stay hospital wards do not wish to move out into community accommodation – quite naturally, they are afraid of the unknown - but once the move has been made a common finding is for the great majority of people to express a preference to stay where they are – they do not want to return to hospital. Preferences are also discussed later.

As noted earlier, policy frameworks that have formally addressed the balance of care for people with long-term needs have generally argued for one particular balance on the basis of evidence or assumptions concerning relative effectiveness. It is argued by many people, for example, that the quality of life of people with long-term needs is best promoted outside institutions. In some countries it can also be seen that policy makers have used evidence or (more commonly) made assumptions about the comparative costs of institutional and community settings. A further set of barriers and facilitators, therefore, comprises the real or assumed relative costs and outcomes of the different care settings. It is important to make that distinction between real or assumed differences, because much policy has been built on extremely fragile foundations of evidence, and subsequent experience has often shown earlier assumptions to be unfounded, or unduly optimistic or pessimistic. The evidence about outcomes and costs in considered on pages 57 *et seq*.

Some of the biggest barriers to changes to the balance of care are constraints in supply, and among them perhaps the most prevalent and most difficult is a shortage of suitably skilled staff (on the assumption – that of course needs to be checked – that families will often not be able to provide much of a direct care role, or will not be able to respond to all of a relative's needs). These supply constraints are described on pages 75 *et seq*, starting with discussion of family roles and the availability of informal care, and then moving on to discuss human resources – the difficulties of recruiting and training sufficient staff. There are other supply constraints to consider, for example relating to capital investment, which are discussed later on pages 78 *et seq*.

In many countries policy in the past was to locate large institutions some distance outside urban areas, whether because of the availability of cheap land or existing buildings, or to hide away people perceived as social problems. Communities built up around the institutions, with the majority of people living in those communities directly or indirectly economically dependent upon them. The large hospital was the single most important source of employment. Closing the institutions can therefore have major negative economic impacts on a community, just as closing a coal mine or major factory can devastate a local economy. Conversely, of course, the development of community-based facilities for disabled people can be a valuable job creation programme. One barrier to changing the balance of care is therefore the local economy. This is discussed on page 78.

Because many institutions are old, and indeed many have been allowed to deteriorate over the years, the value of many institutional buildings today is very low. They have little value in alternative uses: in economic terms, the opportunity cost of using the buildings as long-stay institutions is actually quite low. This consequently represents a further barrier to change and these opportunity costs issues are discussed on pages 78 *et seq*, where the need for adequate capital investment in community facilities, and the timing of that investment, is also considered.

The arrangements that transfer the money from the finance-raising agency (often the tax-raising ministry of central government, or the social insurance fund) to the providers of services on the ground, can create all manner of incentives and disincentives to change the balance of care. A linked issue is whether funding should be protected in some way – such as the ring-fencing of resources released when an institution closes to ensure that they are only used to support service users who would have lived there. These issues are discussed on pages 80 *et seq*.

The incentives and disincentives created by different funding flows, and perhaps the need for protection of budgets, become that much more complex in systems characterised by multiple funding sources. As noted earlier, many people with long-term needs require support not just from a health or social care agency, but also have needs in relation to housing, income support, education and perhaps other areas. Co-ordination of different funding sources can be a major barrier to change. Linked to that problem is the challenge that has grown up around performance assessment, part of a 'new managerialist' approach to policy that is characterising some European countries, such as England. Those performance targets can create incentives for agencies to pursue better practices, but can also become barriers to progress. These issues are discussed on pages 85 *et seq*.

Policies and plans

As many people have remarked, it is relatively easy to close an institution but very much harder to replace it with a coordinated collection of community-based arrangements that offer the support and opportunity needed and wanted by disabled people. Key ingredients for the successful replacement of institutional by community care are a national (or perhaps regional) policy framework and detailed local plans for transferring care out of an institution and into a well-prepared community, both of which should embody positive but realistic visions for the future lives of individual people. Obviously, both should also include economic ingredients: policies without funding commitments and plans without resources are nothing more than delusional optimism or political hot air.

International context

International frameworks and conventions provide an important context for national policy-making. In most European countries, disabled people (using the term broadly) do not enjoy the same opportunities and rights as the rest of the population. The primary international sources of human rights and their relevance for independent living are set out in Table 12 (reproduced with permission from Parker 2007[76]). Many disabled people have not had their rights protected despite the binding nature of the treaties that established many of these declarations.

There have also been international declarations for particular groups of people, such as the 'Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Care' adopted by UN General Assembly resolution in 1991, setting out the basic rights and freedoms of people with mental health needs and anyone admitted to psychiatric facilities, linked to the 1996 declaration on economic, social and cultural rights. These principles cover such topics as criteria for determining when someone has a mental illness, protection of confidentiality, care standards, rights of people in institutions and resource provision.

At the European level, there are is the 1950 European Convention on Human Rights and Fundamental Freedoms, covering the 46 countries in the Council of Europe, and there are of course European Union statutes, principles and guidelines, such as Article 6 of the EU Treaty and the Charter of Fundamental Rights. The European Commission's 2005 Green Paper on mental health put human rights at the centre of its proposals, linked to ensuring respect, combating stigma and discrimination, promoting equality and social inclusion, and encouraging participation in decision making. Promoting community care was fundamental to the proposals. The Green Paper was itself built on the declaration emanating from the 2005 Helsinki Conference of European Health Ministers (WHO Mental Health Declaration for

Europe, ‘Facing the challenges, building solutions’). The raison d’être of an EU strategy in the mental health field is that it would add value to the actions of Member States acting alone.

Of course, none of these declarations and sets of principles will be worth much if not implemented, and there are very few sanctions available to international bodies in the event of non-compliance. Thus ‘cage beds’, chemical restraints, solitary confinement, physical and sexual abuse, overcrowding and electro-convulsive therapy without anaesthesia or muscle relaxants continue to characterise many institutions in Europe, in blatant contravention of internationally agreed principles. Although there are many barriers to individual residents whose rights have been breached pursuing claims, under the European Convention on Human Rights they can take their complaints to the European Court of Human Rights.

Policy framework

One tier down, at national level, a very relevant question is whether there exists a policy relating to the care and treatment of mental health service users, people with intellectual disabilities, people with physical or sensory impairments, and so on. In particular, is there a national policy (possibly also with devolved regional or local responsibilities) to change the balance of care between institutional and community settings? Without such a policy it is unlikely that there will be wholesale changes to this balance of care, and it is also more unlikely that any changes that *do* occur will be structured, coordinated and ultimately successful in promoting the well being of individuals.

National policy initiatives in the three study countries are described in other parts of this report, but would include Law 180 in Italy (1978) which closed the psychiatric hospitals, the Expert Commission (1988) in Germany which set targets for developing an integrated community-based service, and, in England, the National Service Frameworks for mental health and older people, and the *Valuing People* White Paper for people with intellectual disabilities. The World Health Organization argues that having a national policy on mental health, for example, is imperative for raising awareness and securing resources, but it must be up to date, it must command widespread acceptance, it must be sufficiently broadly based to encompass the actions needed to meet the multiple needs of disabled people, and it must be implemented (whereas all three countries offer evidence of regional or local variations in implementation). It should also be drawn up in consultation with the people likely to be affected by it.

Table 12 International human rights and independent living

Instrument	**Relevance to Independent Living**
Universal Declaration of Human Rights 1948	Range of civil & political rights and economic, social and cultural rights, such as: right to life and liberty, the right to marry and found a family, the right to work and the right to an adequate standard of living. Article 1: *'All human beings are born free and equal in dignity & rights…'*
UN International Covenant on Civil & Political Rights 1966	Includes: right to life; right to liberty; right to marry and found a family; right to take part in the conduct of public affairs; right to vote. Key principle of equality: *'sometimes requires States parties to take affirmative action in order to diminish or eliminate conditions which cause or help to perpetrate discrimination…'*[1]
UN International Covenant on Economic, Social & Cultural Rights 1966	Includes: right to work, right of everyone to achieve the highest attainable standard of physical and mental health. In relation to disabled people, the obligation is to *'…take positive action to reduce structural disadvantages and to give appropriate preferential treatment…in order to achieve the objectives of full participation and equality within society for all [disabled people].'*[2]
UN Convention on the Rights of the Child 1989	Article 23: recognition that all disabled children *'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'*
UN Convention on the Rights of Persons with Disabilities 2006 (not yet in force)	Article 3 sets out the general principles, including: '*Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*'; Article 19 provides for the recognition of '*the equal right of all persons with disabilities to live in the community…*'
UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1990	Participation is a core theme. Preconditions for participation include the need to *'ensure the development and supply of support services…to assist [disabled people] to increase their level of independence in their daily living and to exercise their rights'* (Rule 4). Target areas for participation include education (Rule 6), employment (Rule 7) and family life and personal integrity (Rule 9). States should *'create the legal bases for measures to achieve the objectives of full participation and equality for [disabled people].'* (Rule 15)
European Convention on Human Rights 1950	Includes a range of civil and political rights such as the right to liberty, right to private and family life and the right to marry and found a family. In some circumstances obligations may extend beyond refraining from interfering with rights to requiring States to take positive action to protect such rights, for example assisting disabled people with their housing (see Marzari v Italy (1999))

European Social Charter 1961 (Revised Charter 1996)	Includes: right to work, the right to a fair remuneration, right to vocational training and the right of the family to social, legal and economic protection. Article 15 provides the right of *‘physically and mentally disabled people to vocational training, rehabilitation and resettlement’*. The wording of Article 15 in the Revised Social Charter is much stronger – *‘The right of persons with disabilities to independence, social integration and participation in the life of the community.’*
European Union Charter of Fundamental Rights 2000	Article 26: *‘The Union recognises and respects the right of persons with disabilities to ensure their independence, social and occupational integration and participation in the life of the community.’*

[1] CCPR General Comment 18, Non-discrimination, 37th Session 1989

[2] CESCR General Comment 5, Persons with disabilities, 11th Session 1994

Closure and development plans

Moving from the international and national contexts to the local situation, the key question is whether there is a plan for the closure of a hospital or other institution. Such a plan would (if well formulated) provide a long-term strategy for moving all residents out of the hospital, redeploying staff, shifting the balance of funding and developing appropriate community services. Without a plan it is obviously possible to close a hospital, but there will almost certainly be many more mistakes along the way. Law 180 in Italy, for example, introduced important reforms but was not coordinated centrally, leaving regional administrations to devote very different resources to its implementation and leading, for example, to different patterns of ‘trans-institutionalisation’. Similarly, the closure of the long-stay hospitals in England prompted highly variable local responses to the development of replacement services and supports.

Detailed local plans for closing an institution and for developing a better community-based care system should range over many dimensions, and should include at least the following ingredients:

- A realistic timetable for transfer of people from one setting to another, taking full account of individual needs (necessarily assessed in the institution, but to relate lives outside in the community) and to preferences (see below). Some people will need longer preparation for the move from a hospital where they lived much of their lives.
- A realistic timetable for the transfer of funds between hospital and community budgets, including – if necessary – out of the health system.
- A realistic timetable for the redeployment of staff, taking account of preferences, employment legislation, and the skills needed to work in different environments.
- Well-developed plans for developing (hence building and staffing) a range of community accommodation settings and support services, cognisant of the preferences of individuals but also necessarily constrained by the availability of resources.
- Plans for selling off hospital and other buildings and/or sites to realise capital that could potentially be ploughed into new community services.

- Funds for the early investment in community services – before any savings have accrued from reducing the population of the institution, and certainly before selling off the site – to ensure that capital facilities and trained staff are ready before any service users move out.
- Full and informed consultation with families (where they are still in contact with service users), although being careful to balance the preferences of family members with those of individual service users.
- Preparation of the community, tackling what are usually negative attitudes towards community care.
- Most importantly, plans to inform the individuals affected by these changes as to the future possibilities and to engage their full and informed participation in decision-making.

Vision

One other area to mention in the context of this discussion of policies and plans is *vision*. Evidence from many countries demonstrates a disappointing lack of vision about what could be achieved in community settings, and particularly some often very pessimistic views as to the abilities of individuals to lead independent or semi-independent lives. Of course, many long-stay hospital residents have become institutionalised, losing life skills that they may have had before admission. It is therefore hard to assess the likely future needs and capabilities of individuals from the unreal confines of a remote, unchallenging institution that offers few opportunities for self-expression or independence. In consequence – and also as a result of an understandable desire not to take unnecessary risks – there has been a tendency to move people from institutions into more highly staffed settings than are eventually found to be needed.

Preferences

Well-prepared local plans would include full consultation with the people affected by them, most importantly the people who use the services. The preferences of service users can be both barriers to and facilitators of change. So too can the expressed or assumed preferences of families and the wider society. For example, hospital residents often do not want to leave the institution, but once they have established themselves in the community they do not want to move back. Families are often very anxious about their disabled relatives moving from the protected environment of a long-stay hospital into the unknown dangers of the community (especially when communities or the individuals in them demonstrate quite hostile attitudes to disability and to the location of facilities for disabled people in their neighbourhoods, perhaps more marked in England than in Germany and Italy). Such negative attitudes have fuelled calls for what has been called ‘trans-institutionalisation’, such as the movement of people with intellectual disabilities from the old ‘mental handicap hospitals’ in the England and other parts of the UK to village communities, or the movement of people with challenging mental health needs from psychiatric hospitals to secure environments.

Societal preferences are important because of the way they influence the attitudes of the elected politicians who eventually have to take decisions about closing institutions. Entrenched views held by the general public concerning the nature of many disabilities and their implications (including often rather exaggerated concerns about dangerous behaviour), and hence about closing institutions and integrating disabled people into ‘ordinary’ communities can be very powerful. So, too, can the views of service professionals, which again can sometimes be negative and myopic. Societal preferences of this kind are important because, although not necessarily economic barriers/facilities themselves, they do have economic consequences. Among the more obvious such consequences are the pressure to open quite restrictive, and hence quite expensive, environments (such as medium secure units in England); and, secondly, the reluctance to devolve powers of decision making and budget holding to individual disabled people (through such mechanisms as person-centred planning, direct payments and individual budgets in England), and instead to require these people to stay within the conventional and paternalistic care systems which appear to be more costly to operate (evidence).

Learning and adaptation

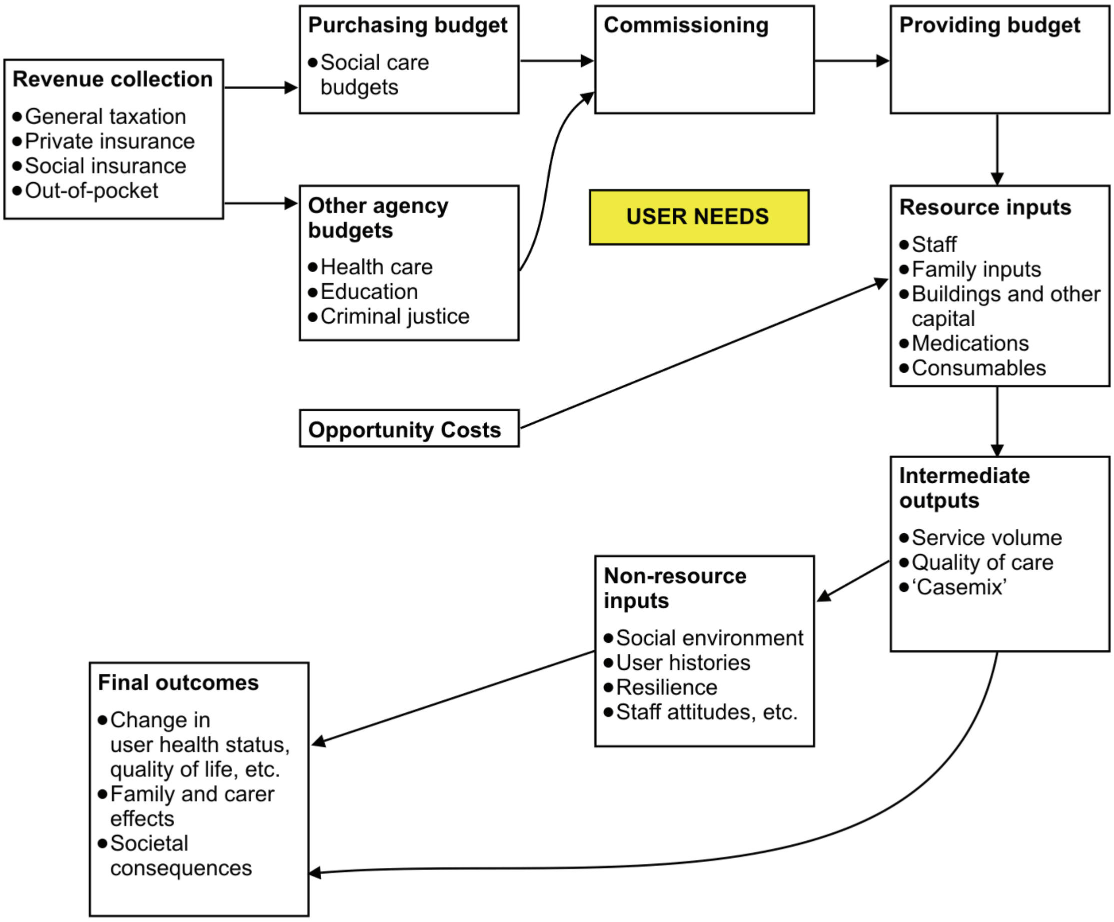
A final comment on plans for developing services in the community to replace institutions is that it is important to recognise that initial plans will usually need to be adapted as experience and knowledge are gained during the process of transition. At the outset, plans are often constructed under conditions of maximum ignorance and minimum experience. This means that they are often more conservative than they need be and will need to change as decision-makers learn how to provide successful services in the community. For example, the first proposals to close Darenth Park Hospital in England were to build new, smaller institutions[58]. As some services supporting people in ordinary housing were successfully developed, this plan was abandoned in favour of services for all in the community. By then, the first four new institutions were being planned and were built (though smaller than originally envisaged). Twenty years later, those institutions are seen as a mistake and are closing.

Costs, needs and outcomes

The production of welfare

In considering the economic potential for, and consequences of changing the balance of care for disabled people, it is important to ensure that discussions and decisions are not solely based on costs but on the interconnections between costs, needs and outcomes. It is therefore helpful to locate the discussion of evidence and its practice and policy implications within a suitable conceptual framework. The structure illustrated in Figure 1 – the production of welfare framework[77,78] – is a simplification of the myriad links between budgets, the staff and other resources they are used to hire or purchase, the services that are thereby produced, and the health, behavioural and quality of life outcomes that hopefully will result for service users, their families and relevant others. The framework thus helps interpretation of the available evidence and to identification of the issues faced by decision makers.

Figure 1 The 'production of welfare' framework



The framework shows the connections between a number of entities:

- the needs of individuals for care and support, defined by reference to nationally and locally developed policies, agreed service objectives and the views of service users and relevant others;
- the resource inputs used in promoting better health, improved quality of life and so on – these are mainly staff, physical capital, medications and other consumables;
- the costs of these resource inputs expressed in monetary terms;
- the service volumes and qualities (perhaps weighted in some way for the needs and other characteristics of users) that are achieved ('produced') by combining the resource inputs – these can be called intermediate outputs;
- the final outcomes from prevention, treatment and care, principally outcomes for individual service users and others gauged in terms of symptom alleviation, changes in behavioural patterns, better personal and social functioning, improved quality of life (including for families) and perhaps some wider social consequences;
- the non-resource inputs, which do not have a readily identified cost (since they are not directly marketed) but which exert influences on user outcomes and also mediate the influences of the resource inputs. Examples would be the social milieu of a care setting, service users' personal histories (especially their previous treatment/care experiences) and staff attitudes;
- the commissioning or funding links between costs (or budgets) and the intermediate (service) outputs; and

- revenue collection, defined by the World Health Organization[79] as 'the process by which the health system receives money from households and organizations or companies, as well as from donors'.

This 'production of welfare' framework emphasises that the success of a care system in improving health and quality of life depends on the mix, volume and deployment of resource inputs and the services they deliver, which in turn are dependent on the finances made available through various funding or commissioning routes.

What is included in the outcomes (or final outcomes) category will depend on the group of individuals whose care is under discussion – for people with mental health needs it would be likely to include symptom improvement as well as personal functioning, whereas for people with intellectual disabilities it would be relevant to focus on behaviour or independence. Common to all service user groups is the need to consider quality of life.

In considering resource inputs and costs, it will generally be necessary to range quite widely over a number of dimensions. The following distinctions should probably be made:

- Costs of services provided by the lead agency; eg mental health services provided by the health system. These are usually called direct costs.
- Costs of services provided by other agencies; eg mental health services provided by the social welfare system. These are usually called indirect costs.
- Costs of support provided by families and other informal carers. These are usually called indirect or maybe hidden costs
- Costs of lost opportunities; eg lost productivity because carers have to give up work and lose income. These are also indirect or hidden costs.
- 'Costs', in a colloquial sense, of having an unmet need or burden; eg the 'stress' costs of caring. These are often refereed to as intangible costs.

The key questions on costs, needs and outcomes

What do policy makers need to know when contemplating the economic relative costs of institutions and community-based care systems? There are essentially four key questions which policy makers need answering:

Question A: Is the cost of care in the community today less than the cost of institutional care?

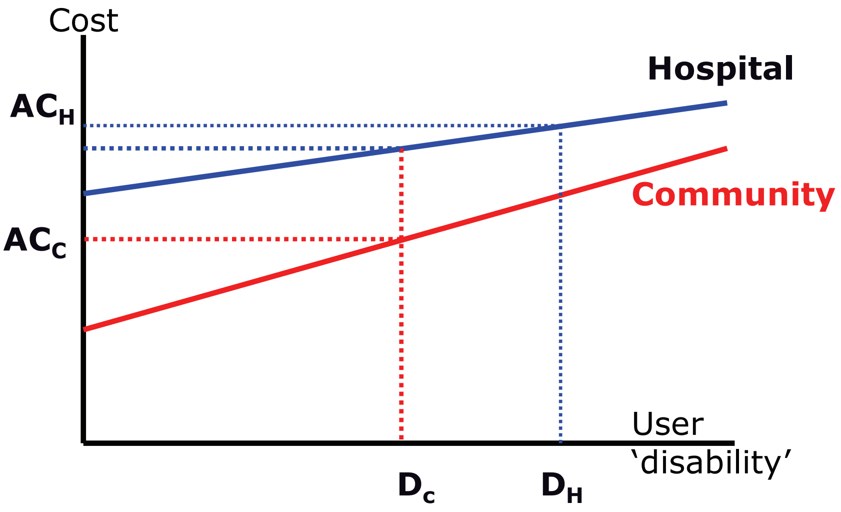
Question B: Are the costs of community and institutional care higher for people with more clinical, social or behavioural problems; i.e. with greater needs?

Question C: On a like-with-like basis – ie adjusting for users' needs – is the cost of care in the community lower than the cost of institutional care?

Question D: If community care is more costly than institutional care, is it nevertheless more cost-effective because better outcomes are achieved for users and families for which it is considered 'worth' paying extra?

It is helpful to illustrate the hypotheses behind these questions formally and diagrammatically (see Figure 2).

Figure 2 Costs and disability in hospital and community



The two solid, upward-sloping lines in Figure 2 represent the (for the moment, hypothesised) relationships between costs and the clinical, social and behavioural characteristics of individuals (called 'degree of disability' for short, in order to imply an ordering), one for people in institutional care (here, long-stay hospital care), the other for people in the community. Movement from left to right along the horizontal axis indicates an increase in disability, and movement up the vertical axis indicates higher costs. As drawn, the two cost lines assume that cost and dependency are positively correlated in both settings. Whether this is a valid assumption is the subject of question B. The shape and position of the two cost lines assumes that, on a like-with-like basis, hospital provision is more costly than community care whatever the severity of mental health problems or degree of dependency, which is question C.

Points D_C and D_H denote the average disability levels in community and hospital settings. It is assumed that 'average degree of disability' among the hospital in-patient sample is greater than 'average degree of disability' among the community sample. There is evidence to suggest that this is the case (eg Lelliott *et al*[65] for mental health care in England). The costs marked AC_H and AC_C are then the observed average costs of hospital and community care, covering both their accommodation facility and non-facility components.

The reason for making the distinction between questions A and C is because settings and services differ in important ways, and people are not randomly allocated to services. Instead, they are, or at least they should be, offered services to meet their needs or preferences. Similarly, staff are not randomly employed: they are chosen so that their skills match the needs of the organisations. Hospitals or other institutions that are closing do not randomly discharge people to community settings: they choose and place people carefully, or at least they should do[80,81]. In other words, things do not happen randomly and groups of individuals in two different settings should not be expected to be identical in their needs or in other characteristics that could have a bearing on costs or outcomes. And if people in two settings are not identical then research should make adjustments for the differences between them, that is to ensure like-with-like comparisons. In clinical research this is often sought through use of a randomised controlled trial, but there are circumstances when such a research design is very unlikely to be feasible – and may even be seen as unethical – such as when looking at the consequences of shifting the balance of care. The alternative would therefore be to use quasi-experimental 'matching' or statistical adjustments to observational data.

Figure 3 Friern Hospital closure: cost of community-based care for each annual cohort of 'leavers'

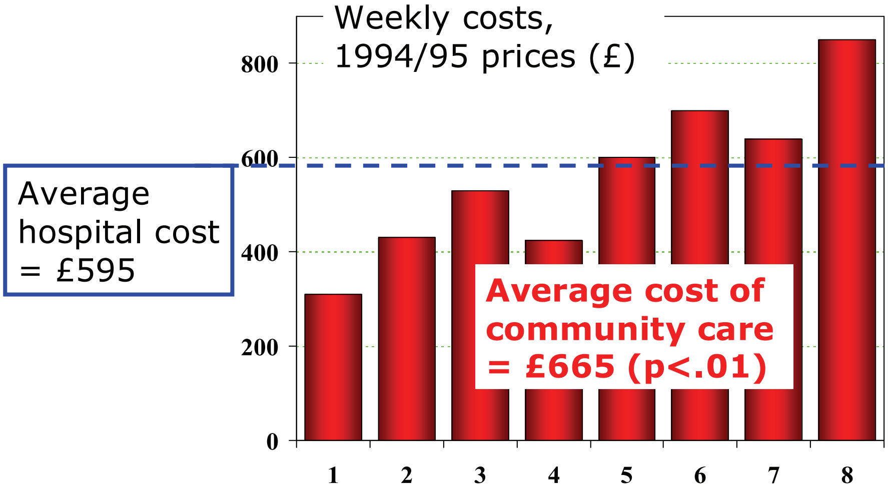


Figure 3 illustrates this using a study of people who moved out of Friern Hospital, a large psychiatric institution in north London, following the announcement of a closure plan in the mid 1980s[82]. When these people were interviewed a year after they made the move to the community, data were collected on their accommodation arrangements and the services they used. Those services were costed. Looking at each successive annual cohort of leavers – the people who left Friern in each of the eight years that it took the hospital finally to close following the announcement of closure, it is clear that residents were not randomly selected for the move. Rather, the people who moved out in the first few years were more independent (less 'disabled') than those who moved out later, and needed less support and used fewer services in the community, so that their costs were lower.

Questions A to C need addressing because the answers to them will tell decision makers what they can expect by way of changes to the costs (and overall level of expenditure) if they change the balance of care. Question D goes further and introduces the issue of outcomes. Some policies appear to be based more on costs than outcomes, while others give more emphasis to outcomes. The right way to proceed is to ensure that both sides of the 'production of welfare' relationship are taken into account.

How is this achieved? The cost-effectiveness argument should proceed as follows:

- If community care is *more effective* than hospital care, and if it is also *less costly*, then there should be no doubt as to the desirability of changing the balance of care on these cost-outcome ('efficiency') grounds.
- If, however, community care is *more effective* but also simultaneously *more costly*, then a decision will have to be made as to whether the better outcomes warrant spending more money on supporting this group of people. The decision maker has to be persuaded to invest more money in community care than will be saved from running down the institution on the grounds that the improvements in the quality of life for the people affected are large enough to justify this course of action.
- If community care is *less effective* and *more expensive* than hospital, then there is no economic case for shifting the balance of care from the latter to the former, although of course there may be other powerful reasons for favouring such a move.
- Finally, if community care is *less effective* but also *less expensive* than hospital, then the might be a narrow cost-cutting case for shifting care from hospital to community, but it would leave service users living in worse circumstances, and would hardly be likely to find favour without raising difficult moral and other issues.

The evidence

So what does the evidence say? What answers are there to questions A to D above? This section presents evidence from the three focus countries, England, Germany and Italy. There is much more empirical evidence available for England than for the other two countries. However, there is no indication to suggest that the broad conclusions that can be drawn are necessarily different between countries. The discussion of evidence distinguishes three groups of people using services:

- Mental health service users
- People with intellectual disabilities
- People with physical disability or sensory impairment

The available economics evidence is not evenly distributed across these groups. It is most plentiful for people with mental health needs, and fairly plentiful for people with intellectual disabilities. Some insights are also offered drawn from services for children and older people, but there is relatively little economic evidence about the balance of care for these groups.

Mental health services

Looking first at services for people with mental health needs, the available evidence can be arranged into a number of categories:

- Studies that compare hospital and community settings at a particular point in time, using cross-sectional designs
- Studies of hospital closure that have followed people from their residence in a psychiatric hospital to their new lives in the community

- Studies of service models that seek to divert people away from hospital admission by providing more intensive or better targeted support in their own homes
- Studies of differences between types of provider, particularly state vs non-state
- Studies of cost variations

As noted earlier, the review is dominated by evidence from England. Although there are certainly useful studies from Italy and Germany, the volume and span of available evidence are both much more limited. In the Italian case at least, this is partly a question of timing – there was almost no research – anywhere in the world – looking at economic aspects of mental health services and policies before the mid/late 1980s, and by the time that such work was beginning most of the psychiatric hospitals in Italy had closed.

Cross-sectional comparisons
The most comprehensive cross-sectional studies in this area were carried out in eight areas of England and Wales in the mid 1990s, and across the whole of Italy in the last few years. The English and Welsh study covered almost 400 community accommodation facilities and psychiatric inpatient wards[65,83,84]. It provides direct answers to questions A to C.

Before any adjustment was made for any differences in residents' characteristics between settings, the costs of hospital care were found to be significantly greater than the costs of care in community accommodation[83]. This comparison addresses question A. The seemingly high costs of psychiatric inpatient care helps to explain some of the historical and current interest in England and other countries in reducing hospital-based services in favour of alternatives in the community[85,86].

However, as noted earlier, care needs to be taken to compare like-with-like. To address question B a series of multiple regression analyses were estimated. *Inter alia,* these equations tested whether the cost of an individual's care is associated with:
- demographic and situational characteristics (age, gender, ethnic group, marital status)
- previous living situation (with whom they were living prior to admission)
- previous psychiatric service history, especially in-patient admissions
- symptoms, daily living skills, social interaction and other needs-related characteristics; and
- current legal status (under the Mental Health Act).

Between 11 and 45% of the observed variance in inter-individual costs could be explained statistically by variations in resident characteristics. There were numerous significant positive associations between measures of mental health symptoms and cost. However, there were also some significant negative associations, for example aggressive behaviour and daily living skills, which would not be expected of a care system that sought to match resources perfectly to needs. Some of these 'unexpected' correlations may be caused by collinearity between variables or the large number of tests conducted[87].

With the data from this study it is not possible to address question C comprehensively, and extrapolation to broader contexts may not be easy. The study did not cover every hospital in-patient; only those deemed by local staff to be inappropriately placed or continuously resident for six months or more. There may have been some hospital residents with symptoms or needs that would imply rather different cost profiles than those covered by the survey. Nevertheless, the study suggested that, on a like-with-like basis, the cost of community-based care was lower than the cost of hospital care for all people with mental health problems covered by the survey, irrespective of severity of symptoms and needs, and even with 7-days-a-week, 24-hour nursing cover. It should be noted that at least two other studies – one in Germany[82,88], both described in more detail below – have shown that for people with *more severe* mental health problems, the cost of care in the community is greater than hospital care.

The cost projections at the higher end of the dependency/severity range are linear extrapolations (using the estimated regression equations) from what were then the hospital and community populations. These extrapolations suffer from at least two limitations. First, in reality there may be non-linearities beyond the present population range which would, say, push up the community cost of people who were at the time living in hospital or pull down the hospital costs of community residents. Secondly, there is a lot of statistical 'noise' in some of the regression equations; that is, quite high proportions of unexplained variance. One other and very important qualification to these findings is that the cross-sectional design allowed quality of care to be assessed (and indicators of this construct were included in the statistical adjustment of costs when addressing question C), but did not allow outcomes to be measured, since these require changes over time to be examined.

One further component of this large English and Welsh study is worth noting, comparing the costs between local authority, voluntary and private community mental health providers[89]. In London, voluntary sector facilities appeared to be more cost-efficient, whereas outside London both the voluntary and private sectors had cost advantages over local authority provision.

Hafner and an der Heiden[88] compared the mean costs of comprehensive community care for a cohort of people in Mannheim with people with continued hospital care of the same length. Community care costs were less than half the cost of hospital. When they looked at the pattern of individual care costs in the community, there was a steeply rising trend:

> "which finally exceeded the threshold value represented by the costs of continued in-patient care. In eight cases (6% of the cohort) the cost of complementary [community] care was higher than that of traditional hospital care … Community mental health care, as compared with continued hospital care, becomes considerably cheaper if severely ill and disabled patients needing particularly intensive care are not discharged from hospital" (p.15).

Given their high level of needs, the authors suggested that it would be appropriate for these patients to remain in hospital where 24-hour medical and nursing care are available as well as good accommodation, occupation and leisure time and rehabilitation activities (p.16). However, it is likely that community-based alternatives to such continued hospital residence could in fact be developed, as they have been, for example, in intellectual disability services.

Hospital closure

A few longitudinal studies have been completed of service user outcomes and resource consequences of shifting long-term care to the community[82,83,90-92]. These studies of the rehabilitation of long-stay inpatients in England and Northern Ireland have found community-based care to be more cost-effective than hospital care for most people. This result applies particularly to those with less severe mental illness or fewer dependencies[93]. However, there were found to be a number of long-stay inpatients with very challenging needs who are more costly to accommodate in community settings (or at least those community settings then in use) than in hospital, even though their clinical and social outcomes do show improvements. Success for these people depended on having sufficient staffing intensity[94-96].

The most comprehensive evaluation of community-based care for former long-stay inpatients that has been conducted looked at the closure of two North London hospitals. The outcome findings suggest that former inpatients were enjoying a quality of life at least as good as in hospital one and five years after discharge (initially this was by comparison with matched controls in hospital, but later became a mirror-image design). There were no problems with higher-than-normal mortality, or with homelessness and crime. Accommodation stability in the community was impressive, and care environments (as rated by researchers and residents) were much better than in hospital. Social networks were stable: a minority of people gained in this respect, but most were not socially integrated into local communities. Hospital readmissions were common (38% had at least one readmission over a five-year period). Careful examination of clinical outcomes revealed striking stability over time in both psychiatric symptoms and social behaviour. Patients strongly preferred community living to hospital[97,98].

The associated economic evaluation found that many services were used in the community (see Table 11 above), with patterns of service use changing over time. Two case studies are provided in Table 13 and Table 14. The full costs were no different between community and long-stay hospital care[82]. Pooling the cost and outcome findings suggested that community care was more cost-effective. Higher cost community care packages appeared to be associated with better individual outcomes. Care appeared to be more cost-effective in the public than in the private sector (see below).

This finding of no cost difference but a cost-effective advantage is consistent with what some others have argued on the basis of observation. As de Girolamo and Cozza[64] conclude in their discussion of the Italian experience:

> “Political and administrative commitment is necessary [when shifting the balance of care]. Community care is not, and will never be, a cheap solution (although mental hospitals with minimally acceptable standards of care are expensive). Indeed, if community care is to be effective, investments have to be made in buildings, staff, their training, and the provision of backup facilities” (p.211).

Table 13 Andrew – from psychiatric hospital to independent living

Andrew is 39 years old and lives alone in a flat rented from a housing association. He has no formal or informal personal assistance. He has gastrointestinal problems that require regular monitoring by his primary care physician and he takes medication for a skin problem. Andrew has no particular behavioural problems.

Services received	**Weekly cost (2006 prices)**	**Description**
Social Care - Social work	£22.00	Social worker and link worker visit every 2 weeks for 30 minutes
Health Care Primary care physician Chiropodist Hospital outpatient clinic	 £2.20 £0.50 £21.00	 10 surgery appointments in the past year Two visit in the past year One appointment each month for a check-up and for depot injections
Other services - Housing officer	£8.00	Visits every two weeks for 15 minutes
Accommodation	£155.00	Managed by the housing association
Living expenses	£145.00	Disability and income-related welfare benefits
Total weekly cost of support	**£353.00**	

Table 14 Bryan – from psychiatric hospital to high-support community home

Bryan is 51 and lives with seven other residents in community home with high levels of staff support. The home is managed by the local NHS community services Trust. Bryan needs daily care for respiratory problems. He is a heavy smoker and has twice been responsible for causing fires. He becomes verbally aggressive at least once a month and has episodes of extreme agitation during which he becomes incontinent. He can concentrate for short periods only and tends to be socially isolated.

Services received	**Weekly cost (2006 prices)**	**Description**
Social Care - Social work	£1.40	
Health Care Depot injection Chiropodist Dentist Optician	 £7.60 £2.00 £0.20 £0.30	 Cost of drug given by staff Visits monthly; sees four residents each time One check-up in the past year Once sight-test in past year
Other services - Day centre	£5.00	Drops in for about one hour a week
Accommodation	£1,737.00	Cost per resident week. 82% of total costs are absorbed by staff costs.
Living expenses	£42.20	Personal allowance and bus pass
Total weekly cost of support	**£1,796.00**	

The longest running hospital closure/replacement study is the twelve-year follow up of people who moved from long-stay hospital residence to a community setting under the auspices of the UK Government's Care in the Community demonstration programme, launched in the 1980s [80,90,99,100]. Twelve years after people left hospital, these individuals were living in a range of settings: 39% in residential or nursing homes, 17% in less intensively staffed group homes or small hostels, 34% in minimum (formal) support settings such as adult foster placements, unstaffed group homes, sheltered housing and independent domestic housing, and the remaining 9% were permanently resident in psychiatric wards.

Over the period, a number of abilities had declined (mobility, ability to wash, bathe and dress, and general appearance), but conversation and social interaction had improved. Ratings of co-operative behaviour had decreased. There were marginally significant increases in the reported incidence of odd gestures and mannerisms, obsessive behaviour, depression and suicidal preoccupation. There was also a marginally significant increase in the proportion of residents showing a degree of confusion. Nevertheless, the majority of people in the sample were functioning quite well and had relatively few symptoms and behavioural problems. A much higher proportion of users were satisfied with their community accommodation than with hospital, and very few wished to return. Relationships with staff were generally positive, but there was room for improvement. Many users in residential and nursing homes did not feel that they had choices in their lives. The average size of social networks (23 contacts) compared favourably to that reported in other studies. However, networks were mainly staff and other service users. Despite having lived in the community for over a decade, people were still interacting in a community within a community. Residents living in hospital or hostels and small group homes had fewer close and confiding relationships compared to those in other accommodation types.

Many organisations were involved in supporting service users in the community[101]. There was, however, little evidence to suggest that organisations were working together to create support packages that crossed traditional agency boundaries – reinforcing what others have found. For example, people with mental health problems living in social services managed accommodation rarely used services provided by the health service, while those in health service accommodation rarely used social care services. The average weekly total cost per resident remained lower than the long-stay hospital costs. However, the range was considerably wider, suggesting a greater diversity of support arrangements. After standardising for users' skills and behaviour problems, costs in supported accommodation were significantly lower than expected and costs for people living permanently in hospital were somewhat higher than expected. The support costs could not be predicted from the characteristics of users as measured in hospital twelve years earlier. There was no evidence of a relationship between cost and changes in skills, but there was some evidence that the more a person's behaviour had deteriorated over the twelve-year period, the more costly was their package of care.

Differences between provider sectors

Further analyses of data from the North London study looked at quality of care, outcome and costs in hospital and 12 months after discharge by provider sector[102]. For the purposes of those analyses, attention was restricted to the 429 people living in specialist mental health accommodation in the community; ie people in independent accommodation, hospital and community inpatient units were excluded. The different sectors were not accommodating people with identical needs or dependency profiles, but these differences did not appear to account for inter-sectoral variations in costs. Even after adjusting for the effects of resident characteristics, the costs of community care were lower in the private sector than elsewhere, and higher in the NHS and consortium (NHS and voluntary sector in partnership) sectors. Costs in the private sector were almost half the costs in all other sectors, partly because the residential accommodation itself was less costly and partly because people in private facilities used fewer services outside their place of residence.

But it is possibly a third reason for the lower costs in the private sector which is most relevant, and which links to our later discussion of funding flows. In the smaller homes run by owner-managers (in some cases former nursing staff from the hospitals who knew the residents before they moved to the community) the fees paid by public sector purchasers or (at that time, by central government) may not have covered the full costs of residence. Certainly these fee levels were seen as a constraint by many proprietors, and the impression gained during interviews was that some owner-managers were operating at a recurrent loss. The lower costs in the private sector may have been achieved at the expense of lower quality care, for there was strong evidence of fewer opportunities for residents and more environmental restrictions in private facilities, which could not be put down to chance. The NHS and NHS/voluntary sector consortium facilities performed significantly better than other provider sectors by these criteria, although these were easily the most expensive facilities. Whether these quality of care differences worked through to generate differences in user outcomes is not so clear, however, for there were comparatively few changes in health or quality of life during the first year of community residence.

The twelve-year follow-up of the Care in the Community demonstration programme sample found no differences in costs between managing agencies (after adjustment for individual characteristics)[101].

Community 'diversion'

Although the focus in this report is on the potential closure of institutions and their replacement by community-based accommodation and other services, it is important not to overlook the role of community models of care that can 'divert' people away from psychiatric hospital inpatient admission in the first place.

The *assertive outreach* approach first developed in Wisconsin USA has been widely copied and/or adapted in many countries, and also quite widely evaluated. A London modification of the model - the Maudsley's Daily Living Programme (DLP) – looked at seriously mentally ill people facing crisis admission to hospital. A randomised controlled trial found that the DLP produced better outcomes, higher user and family satisfaction, and lower costs than standard care in the short term[103,104], but after four years there were no differences in clinical or other outcomes, or in costs[105,106]. Nevertheless, over the full four-year period the DLP was more cost-effective than standard hospital-based care (inpatient followed by outpatient supervision). Other studies confirm the cost-effectiveness of community-based crisis interventions, which may be seen to have assertive outreach-like characteristics, including one in England[107]. The overall weight of evidence is that forms of assertive outreach that adhere closely to the original Wisconsin model are more cost-effective than conventional hospital-based services or other community arrangements[108,109].

At least one study has found that a variant of *case management* (including intensive case management) is effective and cost-effective[110,111], whilst others do not[107]. However, the UK700 study – a large randomised controlled trial – showed the two approaches to be equally cost-effective, and concluded that reduced caseloads have no clear beneficial effect beyond that achieved with standard case management[112]. There were significant quality of life improvements over a two-year period, but no differences between intensive and standard case management[113].

A London study compared care programmes (essentially a form of care management) administered by either community-based or hospital-based teams following discharge from inpatient care, finding higher costs for the latter without any difference in outcomes[114]. However, the high use of placements in private hospitals in one locality confounded the findings. Other studies of community mental health teams give equivocal results[115-117].

Cost variations

The PROGRES study of psychiatric residential care in Italy has generated a wealth of helpfully recent data on the characteristics of community-based residential facilities, the people who live and work there, and the associated costs. Amaddeo *et al*[118] describe and analyse the marked variation in per resident cost across the sample of 265 facilities from across the whole of Italy. A number of factors were found to be associated with differences in cost, including type of facility, location, size (number of beds) and – at the individual level – the age and psychiatric diagnosis of a resident. As well as variations in the costs of facilities, there were also marked variations in the costs of other services (provided from outside the facility budget) used by residents. These latter costs also followed a certain pattern of variability, linked for example to resident age, diagnosis, level of functioning and whether the resident had previous experience of an acute psychiatric admission.

Using the same PROGRES data set, de Girolamo *et al*[119] described the marked variation in level and pattern of provision across the country, with the typical provision being much lower than found in the similar study in England a decade earlier[65]. Level of provision was inversely correlated with the local provision of outpatient and day care services, but the direction of causality was not clear. Interestingly, relatively few residents of these facilities were discharged to independent accommodation[120]. Residential facilities were seen as the replacement for the mental hospitals that were closed following Law 180, and the question must be asked as to whether long-term residence in such a facility is the most appropriate response to an individual's needs. What appears to be clear is that many people with mental health needs do require 24-hour support/supervision for long periods of their lives.

In another Italian study of the factors associated with variations in the service costs of supporting people with mental health needs, carried out in South Verona, Bonizzato *et al*[121] found significant links between costs, previous psychiatric hospital admission, intensity and duration of previous contacts with the mental health system, being unemployed, diagnosis and a measure of functioning.

The English studies described earlier in this section each looked at the extent of cost variation between individual service users and examined what personal characteristics were associated with that variation (see Knapp[122] for an earlier review and an account of the potential sources of cost variation). There have also been some German studies that have explored the factors associated with cost variations[123,124].The findings are not discussed here, but it is important to note that the marked inter-individual cost differences make it imperative that decision-makers, whether working at strategic level or locally in the organisation of services, take full and appropriate account of the needs and personal circumstances of individuals.

Services for people with intellectual disabilities

Research on services for people with intellectual disabilities can be grouped into three categories for the purposes of this report:

- Studies that compare care settings at a particular point in time, using cross-section designs
- Studies of hospital closure that have followed people from their residence in a 'mental handicap' hospital to their new lives in the community
- Studies of variations in the costs of support.

Again there is much more evidence from England than from Italy or Germany.

Cross-sectional comparisons

Shiell *et al*[125] carried out a large cross-sectional survey of accommodation for people with intellectual disabilities in England. They found that several indicators of the quality of care impacted on cost. Generally, more sophisticated procedures (for example, activity planning for residents and individual personal plans) were associated with higher cost. Where less sophisticated procedures existed for staff training and supervision, however, the cost was also higher. This may be because ill-defined internal procedures for training and support of staff result in higher staff turnover, lower morale and higher levels of staff sickness. One important conclusion to draw from this and other studies is that there are marked cost differences between accommodation settings, in terms of both total and component costs.

A cross-sectional study was carried out of the relative merits of village communities (favoured by organisations such as Rescare, which attracts particular support from families of people with intellectual disabilities), NHS residential campuses (often developed on the sites of, sometimes in some of the same buildings as, long-stay hospitals) and dispersed housing. The settings and residents were drawn from across the UK and Ireland. The economic evaluation included careful cost estimation for each accommodation setting and the comprehensive measurement of all services used by three large samples of people[126]. Accommodation and day activities together made up most (almost 100%) of the total cost of support, the remainder being hospital services and community-based professionals.

Comparison of residential campuses, village communities and dispersed housing schemes found that the campuses were less expensive but also of lower quality. Both village communities and dispersed housing were associated with particular benefits, with different settings appropriate for people with different needs and preferences.

Quality of care was generally not as good in village communities but costs were slightly lower after adjustments were made for adaptive behaviour, challenging behaviour and age. The study supported the development of a range of models, as acknowledged in the UK Government's 2001 White Paper *Valuing People*, provided that residents were given genuine and informed choices about their accommodation.

A recent study by Perry *et al*[127] compared semi-independent living with fully staffed group homes across a number of areas of England and Wales. The total costs of care were almost three times higher in the fully staffed settings compared to semi-independent living for people matched on a range of characteristics (£379 compared to £1076 at 2003/04 price levels). Semi-independent living also offered a range of lifestyle advantages (greater self-determination and independence of activity at home and in the community), but it also has certain risks to the welfare of residents and the authors recommend attention to the need for health, eyesight and hearing checks, for example. Costs in the North-Rhine Westphalia region of Germany for institutional care (stationare Unterbringung) are similarly considerably higher than costs for supported living (around 39000 euro compared to around 7000 euro in 2005; reported by Johannes Schadler at project meeting 2007), and whilst these may not have been adjusted for resident characteristics they again indicate the *potential* for more efficient use of available resources.

Hospital closure

Quite a number of UK studies have estimated and compared the costs of hospital and community-based accommodation for people who were resettled in the community. For example, Korman and Glennerster[58] found that costs were greater for NHS-managed community facilities than for hospital placements. A large-sample evaluation of hospital discharges in Northern Ireland found that community provision was less expensive than hospital care, with statutory sector facilities being the most costly arrangements outside hospital, and private residential and nursing homes the least costly[128]. In another Northern Ireland study, Hughes *et al*[129] estimated the costs to a hospital of the process of community resettlement. Dockrell *et al*[130] compared hospital and community costs for a small sample of people with mild intellectual disabilities, but there seems no possibility of generalising from their findings.

The five- and twelve-year follow-up studies of people resettled by projects in the Care in the Community demonstration programme initiated by the Department of Health in the mid-1980s offer encouraging results. As part of this multiple-client group programme, almost 400 people with intellectual disabilities moved to a variety of community residences through twelve separate local schemes in England[131]. Table 15 shows place of residence for people for whom accommodation could be identified at all three time points[132].

Table 15 Accommodation over 12 years for former hospital residents (n=103)

Accommodation type and definition	**Time since leaving hospital**		
	1 year	**5 years**	**12 years**
Residential / nursing homes - provide six places or more with continuous staff cover by day and waking staff at night	2	7	24
Hostels provide six places or more with continuous or intermediate staff cover by day and sleeping-in or on-call cover at night	44	25	21
Staffed group homes provide 2-5 places with continuous or intermediate staff cover by day and any form of night cover	40	37	41
Unstaffed group homes have 2-5 places with ad hoc or no day staff cover and on-call or no staff cover at night	4	11	1
Adult foster placements have intermediate day support and on-call support at night where individuals have moved in with an established household. In **supported lodgings** individuals move into an established household with ad hoc day staff cover and on-call night staff support. The two are grouped together	5	6	5
Sheltered housing provides individual living units within a larger complex which are rented by individuals and some day and night staff cover is available	6	11	10
Independent living arrangements cover single or group tenancies in domestic housing, including living with relatives or spouse, where there is ad hoc or no day staff cover and no staff cover at night	2	4	0
Hospital - individuals readmitted from community placements.	0	0	1
Unclassified	0	2	0

Over the full period, the research found that the costs of the full support arrangements in the community were significantly higher at the one-year follow-up than in hospital[90], had fallen slightly by five years[133], but were then no different from the (inflation-adjusted) costs at twelve years[132]. No evidence was found at either five or twelve years of any significant association between the costs of support and changes in either skills or behavioural problems between the hospital and community assessments[132,133].

At the twelve-year follow-up point, weekly service costs are as in Table 16, described by broad cost category and type of accommodation. At this twelve-year point, service users were living in a wide variety of accommodation settings, with day-to-day management responsibility for facilities falling to NHS trusts, local authorities, voluntary agencies, private organisations or (in a small number of cases) services users themselves. After standardising for users' skills, abilities and behaviour levels, costs in minimum support accommodation were significantly lower than in residential and nursing homes, costs in staffed group homes significantly higher, and costs in hostels slightly lower. The study also reported quality of life improvements for this cohort of people, suggesting long-term quality of life improvements can be achieved at a cost little different in the long-run from that for hospital care.

Table 16 Total weekly service costs by accommodation type (n=273; 2002-2003 prices)

	Residential/ Nursing home (n=77)	**Hostel (n=44)**	**Staffed group home (n=102)**	**Minimum support (n=50)**
Accommodation and living expenses				
Cost range	£247 to £1676	£187 to £1148	£199 to £2071	£149 to £1581
Mean	£812	£593	£819	£354
Hospital-based services				
Cost range	£6 to £533	£6 to £57	£6 to £686	£6 to £391
Mean	£17	£3	£17	£17
% using hospital services	27%	23%	29%	40%
Day activity services				
Cost range	£1 to £200	£5 to £221	£6 to £426	£9 to £213
Mean	£68	£95	£92	£82
% using day services	70%	84%	77%	78%
Community-based professionals				
Cost range	£1 to £128	£0 to £41	£0 to £220	£1 to £347
Mean	£16	£7	£15	£49
% using at least one service	97%	91%	91%	92%
Total weekly cost				
Cost range	£253 to £1856	£298 to £1349	£348 to £2113	£183 to £1731
Mean	£913	£697	£942	£502

Note: Means are calculated across whole sample, not for users only
Minimum support (final column) includes unstaffed group home, foster placement, supported lodgings, sheltered housing and independent living

One conclusion to draw from this long-term study, and from a number of studies of shorter duration, is that the costs of supporting people do not stand still. As an individual's needs change, so should the service responses to those needs, and so usually will the costs also change. The study summarised above found that needs associated with ageing do not necessarily push up costs greatly. Indeed, quality of life improvements for former long-stay hospital residents were achieved without costs exceeding those previously incurred in the hospital setting. With the increasing longevity of people with intellectual disabilities this becomes very relevant.

Cost variations

Some studies have explored the factors associated with inter-individual differences in costs. A consistent finding is that higher costs are related to higher levels of need. One such study collected data in 1996 as part of a study designed to develop 'resource groups' and 'benefit groups' for people with intellectual disabilities (similar to

Diagnostic Related Groups in research in general health care). Information was obtained on some of the characteristics of over 2000 adults with intellectual disabilities living in residential accommodation supported by eleven NHS Trusts, four voluntary providers (including housing associations) and three large and several small private providers spread across England. Service use and costs data were gathered for a sub-sample of about 900 people[134].

There were marked total cost differences across the sample, ranging from £220 for one person's weekly care to as much as £1570 for another person (1996/97 prices). Multiple regression analyses could statistically explain one third of the observed cost variation, indicating that the services used by individuals are responding in part to the individual characteristics and features of the care settings measured in this study. Nevertheless, two-thirds of the observed cost variation could not be explained (statistically) by the cross-sectional analysis.

Costs were found to be higher for people with more severe intellectual disability and displaying greater levels of challenging behaviour. The cost links are non-linear and interdependent: at low levels of intellectual disability there is a simple positive linear relationship between costs and behaviours; at higher levels of disability (where there were in fact relatively few sample members) there is a slight curvilinear cost-behaviour relationship, although costs are still generally higher for people with more challenging behaviour problems. The impact of intellectual disability on cost is mediated through both the sector of accommodation (there being a lower gradient relationship in the NHS sector than in the private/voluntary sectors) and through the size of accommodation setting (the impact of intellectual disability on cost being slightly less in larger facilities). These significant associations suggest that larger facilities – and these two features are correlated – have greater potential to spread the responsibility for supporting challenging behaviours and intellectual disability, respectively, across the staff complement. This study did not examine the quality of services nor the outcomes for residents in settings of different sizes.

The study also found direct cost-raising effects for sector and size of facility, in addition to those linked to degree of intellectual disability. Generally, NHS facilities were more expensive than private/voluntary facilities, other things being equal. However, as just noted, the cost difference between the sectors was not straightforward, but linked to facility size and residents' intellectual disability characteristics, and caution is therefore needed in drawing conclusions concerning inter-sectoral differences from a sample that draws data from a relatively small number of independent sector providers.

The scale of facility, in this case measured by the number of residents in the home during the year, exerted an influence on cost, with an interesting difference between the sectors. NHS facilities clearly enjoyed economies of scale, with cost being just under £2 lower per resident week for each additional resident in the facility. In part this is because of the inclusion in the NHS sample of some people living in quite large hospital facilities. On the other hand, the voluntary/private facilities appeared to be facing diseconomies of scale, with each additional resident in the home generating an additional cost of £2.48 per resident week across all residents, a seemingly small amount but quite significant when comparing (say) the costs of facilities with five places and 40 places.

From this and a number of other studies it is clear that there are often quite marked variations in costs between individuals, particularly associated with the degree of intellectual disability and the presence and severity of challenging behaviour. Whilst there is a tendency for people with greater needs (defined in various ways) to have higher costs - which suggests some success in targeting – much of the inter-individual variation in cost cannot easily be explained by observed or measured characteristics, perhaps supporting the previously described evidence on unmet needs.

Services for physically disabled and sensory impaired people

There is little evidence from any European country on economic aspects of the balance of care for people with physical disability or sensor impairment. In particular it has not been possible to find any research that addresses any of questions A to D set out earlier in relation to services for this group of disabled people. There have been a small number of studies that have calculated the costs of community-based support for disabled people, emphasising the multi-agency nature of that support and the importance of good coordination between agencies, looking at physical disability[135], long-term neurological conditions[136], young people with complex disabilities[137], other conditions or needs not listed here. Lafuma *et al*[138] looked at people with visual impairment in France, Italy, Germany and the UK, estimating prevalence and economic impact. They found a small difference in rate of institutionalisation (ranging from 7.8% in France to 10.9% in Italy) and in the average annual cost per person (ranging from EUR 8434 in France to European 13674 in the UK). The main cost components were loss of income (productivity), carer burden and assistance in the activities of daily living.

This study is unusual in that it compares across countries, but its findings are fairly typical of the small economics literature in this field: the non-service costs are high, particularly linked to lost productivity because many disabled people are prevented from working, and also linked to the unpaid caring roles of families. Service costs are important for those (relatively few) disabled people in institutional care, but otherwise are often very low despite often quite high levels of need.

Supply constraints

An obvious major barrier to change is the inadequate supply of community services. Is it possible for families and friends to support people with long-term needs associated with disabilities? And if not, are there sufficient numbers of skilled (employed) staff to provide the support? Constraints on the availability or supply of both informal care and paid staff represent barriers to the development of community care.

Families and informal care

As noted earlier, the largest ‘provider sector’ is the collection of families who support their disabled relatives. Family care is important everywhere, and especially in Mediterranean societies. But there are three substantial supply constraints. First, many people who have been long-stay residents of institutions have lost contact with their families, or have only occasional and quite limited contact, so that there is no possibility of their returning to the family home. Second, the psychological, social and economic burdens of informal care can be huge, especially if families are unsupported in their caring roles, and many families are understandably unable to provide the necessary intensity or quality of support for long periods. Third, parents themselves often seek 'independence' – quite appropriately – just as their disabled children might want to establish independent lives.

Evidence from England has described this burden. For example, an influential report on mental health and social exclusion by the Office of the Deputy Prime Minister[139] in England argued that, in supporting people with mental health problems, 'carers themselves are twice as likely to have mental health problems if they provide substantial care' (p4). Two studies based on the Leicestershire Learning Disabilities Register described the high levels of stress reported by family carers, most of them aged 40 or over, and one in six aged 70 or over[140,141]. Female carers of working age reported 40% more limiting health disorders compared to the equivalent general population, and depression, 'bad nerves' and musculo-skeletal problems were commonly reported. Emerson *et al*[142] describe the similarly high intangible personal 'costs' carried by family carers of children with intellectual disabilities. Each of these and other studies has pointed to the link between burden and families' economic status: many families with a disabled member find themselves in straitened financial circumstances, principally because of the restrictions imposed on employment.

Many families of people with physical and sensory disabilities have reported psychological stress and poor health stemming from their caring responsibilities[143], as well as substantial out-of-pocket expenses incurred by families[144,145]. Many parents of disabled children and young people will have had to give up work, cut back on their hours or accept lower-salaried positions[146,147]. The longer that caring responsibilities continue, the more difficult it is for a carer to enter the employment market[148].

Most unpaid carers of older people are women and related to the person being cared for. Changing demographic patterns, family composition, labour force participation and geographical mobility are all reducing the potential pool of such carers[149]. An OECD report has identified these as particular challenges for dementia care[150]. Shifting the balance of care for older people away from institutional services and towards community-based care, which is a policy aim across most European Union countries, will increase the burden on family and other carers. Yet, again there is no shortage of evidence that family and other unpaid carers can incur high real as a result of their caring responsibilities – particularly through lost employment, reduced salaries, and lost pension entitlements – as well as less tangible impacts on health and well-being. Livingston *et al*[151] reported a high prevalence of depression among the carers of older people with depression, dementia or physical disability living in community settings. Buck *et al*[152] investigated the extent and correlates of psychological distress among carers: stress was higher when the older person being cared for had more problem behaviours. Drawing data from five EU countries, Colvez *et al*[153] estimated that three quarters of spouse carers and half of child carers of people with dementia suffered from depression. In the UK, Evandrou[154] found that men and women who provide twenty or more hours per week of informal care have earnings from employment that are 25% lower than the earnings of employed non-carers. Indeed, caring has a lifetime impact on earnings and other income[155].

Supporting carers

European governments are generally alert to the need to improve support for family and other unpaid carers, primarily because the cost of the alternative – staffed care in residential settings or intensive models of home care – is too high to contemplate. Some countries offer financial support for carers, which is becoming more common[156]. It can be provided through tax credits (eg in Spain and the US), social security allowances, grants from social care budgets (eg in France and Sweden), pension credits (eg in Germany and the UK), consumer-directed payments (eg long-term care insurance in Germany and individual budgets in England), or payments from voluntary sector bodies. Of course, these various transfers have opportunity costs: governments need to make a judgement as to whether it is better to provide financial support to carers or invest the same money to employ more paid support staff.

Employment-friendly policies are being introduced in some countries to help carers combine a career with caring responsibilities. For example in Sweden, the 1989 Care Leave Act provided caregivers with a period of paid leave to care for an ill elderly relative. In 1998, an addition was made to the Social Service Act that encouraged local municipalities to support family caregivers. Other carer support initiatives include educational programmes, which can modestly improve carer well being, but need to be combined with support, counselling and respite services. Voluntary organisations play important roles in the lives of some carers by providing support, information, advice and advocacy.

Respite or short break care – in a variety of forms – is central to the support programmes for carers in many countries. There is some evidence from across a range of EU countries that group living arrangements are effective and popular[153]. A recent systematic review found some evidence that respite care for carers of older people can have a small positive effect on carers' perceived burden and their mental and physical health[157]. However, respite care did not appear to affect care recipients or delay their admission into residential care.

Workforce

When families cannot provide the care, formal services are relied upon, which requires the recruitment of skilled staff. One barrier to the development of community-based care systems can therefore be the difficulty of finding enough people with the right skills, including the right people to manage services. Transferring staff from institutions to the community is obviously one option, but these might not be the right people: their attitudes may be too 'institutional', too focused on containment and risk-avoidance and their professional experiences may not provide the right platform for building structures that offer new opportunities for assuming control and improving quality of life. Given that institutions will usually serve people from a wide area, staff may not want to relocate to services in people's home communities. Hospital and other staff may simply not want to work in the new service configuration in the community.

A related problem for some new Member States of the EU is the outward migration of qualified staff to countries that pay higher salaries.

One solution is obviously to pay higher salaries, both to persuade people to move into community care employment (because the low status of care work in some countries has made recruitment difficult), and then to retain them (because staff turnover appears to be a problem in community services). Staff salaries in the care sector are notoriously low in many countries. But there are opportunity costs of paying higher salaries: spending more money on the same number of staff means allocating a larger proportion of the available budget to the support of the same or a smaller number of users, or diverting resources away from other parts of (say) the health, social care, housing or other sectors, even if it simultaneously has the potential to improve staff retention and quality, and hence the quality of care.

A rather different workforce supply barrier can be found in some institutions where the more able residents represent a valuable source of free or cheap labour, either in the institution itself or elsewhere in the local economy (for example working on farms or in factories). This is one reason why the pattern of rehabilitation from hospital to community can be rather counter-intuitive. In fact, it may not be the most able residents who are supported to move to the community first – as was the case in most of the psychiatric hospital closure programmes in England, for example – because these people are seen as too valuable to lose.

Local economic development

When an institution is the only or main employer in a community (in, say, a village or small town), then its closure threatens the local economy. Of course, one option might be to try to build community accommodation and related services in those same villages or districts of towns, and to offer employment in those new services to former hospital employees. But if the community in which the hospital is located has very few other forms of employment, then it is probably also not going to big enough to accommodate many former hospital residents in community settings. More likely, as a large institution closes so its residents will disperse geographically – some of them perhaps back to their 'home' areas – and so too will the jobs need to be dispersed. Closing a large institution therefore almost inevitably means big job losses in the local community. Not surprisingly, the fear of unemployment is a substantial attitudinal barrier to community care among staff, just as a prospective downturn in the local economy is likely to dampen the local municipality's enthusiasm for closure. National or regional governments often recognise the need to offer subsidies to promote investment in communities that have been devastated by, say, the closure of a coalmine, dockyard or large factory, but how often is the same action taken following closure of a large institution?

Equivalently, the development of new community services, particularly those that require quite high levels of staffing (such as care homes and hostels) can offer attractive opportunities for local economic regeneration. Locating new accommodation settings for former hospital residents in particular districts of cities, for example, could boost the local economy.

Opportunity costs of capital

In calculating the comparative costs of institutional and community-based care it is important that appropriate values are attached to the capital resources. As far as new community services are concerned, the task would be to calculate the full cost of building a facility, including acquiring the site, and then spreading that cost over the expected lifespan of the facility. For an institution that might be earmarked for closure, the appropriate estimate of capital cost is the value of the building and site in its best alternative use. If that alternative value – the opportunity cost – is low, it could mean that the overall cost of institutional care is also relatively low, and in turn this could mean that community care looks to be a relatively costly option.

Many of the institutions currently accommodating disabled people across Europe may have low opportunity costs of capital: the buildings are often old, in poor state of repair and with little value in any alternative use. The land on which an institution sits might be valuable if it could be redeveloped for, say, housing in an area where property prices are high. However, many institutions are located in remote areas, and their sites might not be seen as especially valuable. This was found to be the case for many of the former psychiatric and 'mental handicap' hospitals that had closed in England during the 1980s and 1990s. Lowin *et al*[158] found that a large number of former hospital sites were still undeveloped: half of the land on sites no longer in original use was vacant, and 40% of the 40 sites where hospitals had closed were at least 90% vacant. This suggests that most hospital sites did not have very much immediate value for redevelopment. One site that clearly did have a high opportunity cost of capital was that occupied by Friern Hospital in north London, much of which was sold off for housing for a considerable sum, with the remainder being retained for mental health care facilities.

Of course, any revenue generated by the sale of an institutional building or site will not be fully realised until the institution has closed. Meanwhile, capital funds will be needed to buy the sites and erect the facilities (or to make conversions or purchases) for the new community care services so that they are ready before residents of the institutions make the move. In addition, even if it is running down towards closure, it takes time for the running costs of an institution to fall. In fact, statistical analysis of revenue expenditure by 119 English psychiatric hospitals in the mid 1980s suggested that as much as four-fifths of a hospital's average revenue cost per patient might be saved in the relatively short-term as inpatient numbers decline[159]. Not surprisingly, the more rapid the rundown of the hospital towards closure the larger the proportion of revenue cost that can be saved. There are, however, potentially unhelpful dynamics in this process discussed below.

The point to emphasise here is that there will be a need for both 'hump' costs – initial investment in the new community facilities to get them underway – as well as double running costs to resource both the old and the new services in parallel for a few years until the institution has fully closed down[160]. The transition from an institution-based to a community-based system demands very careful *pacing* of the transfer of resources, just as it needs the careful management of the movement of people and staff. Injections of additional money will almost always be needed in the short-term to allow the balance of care to shift. Attempts to alter the balance of care in a 'cost-neutral' way – or, worse, attempts immediately to save money – could result in many people being denied adequate care, or moved into substandard settings with little support.

Funding flows

The term ‘funding’ denotes the routes by which the finances raised from taxation, social or voluntary insurance, or user charges and out-of-pocket payments reach service providers. Four topics are considered under this heading:

- Whether there is a need for a separate or ‘protected’ budget for services for (say) people with mental health needs or people with intellectual disabilities, or whether it is better to have integrated budgets.
- The relative merits of centralised and devolved funding arrangements.
- How services are commissioned or purchased, and with what incentives and advantages.
- Whether there are benefits in introducing consumer-directed (or self-directed) care, where individual service users or carers hold the budgets to access care.

Protected budgets?

When plans are made to close a large institution – such as a psychiatric hospital – it has sometimes been argued that the hospital budget should be ‘ring-fenced’ for mental health services in order to protect this funding from leaking away into other parts of the health care system or to other public policy areas. For example, during the 1990s there was a 50% decline in the number of psychiatric hospital beds in Hungary, no ‘protection’ of the budgets and little development of community services[161].

In England, there were similar concerns when the decision was taken to shift the money that was previously routed to hospitals by central government to what were then local health authorities. One very clear advantage of this re-routing was that it created an incentive for these health authorities to move the people for whom they were responsible out of hospital and into the community, where it was anticipated that better care could be provided at no greater cost (indeed, at lower cost to the National Health Service if former hospital residents were moved into private or voluntary residential facilities, where their accommodation would be funded out the social security budget). However, there was generally no control over how these district authorities used the funds, and it was certainly the case that many of them used the money for services outside the mental health field. This is one reason why ‘dowries’ were introduced by some regional health authorities, effectively sending long-stay hospital residents into the community with an attached and (in the short term at least) protected budget. Box 3 summarises the use of dowry-like protection of funding during the process of transferring care for people with intellectual disabilities from Darenth Park Hospital in England to a range of community settings.

Box 3 Dowry arrangements give an incentive for discharge: Darenth Park Hospital

In the early 1970s Darenth Park Hospital had 1500 beds. During the next decade, the Regional Health Authority aimed to downsize the hospital and upgrade its facilities with a view to eventual closure, but these plans were often shelved due to lack of resources and lack of alternative sites. Towards the end of the 1970s, offers to purchase the Darenth Park site by a cement company speeded up the hospital closure plans with the aim of complete closure of the hospital by the mid-1980s. Both parents and staff were less enthusiastic about the change of service. The purchase offer met with strong local opposition and did not go though but plans to close the hospital remained, albeit with a slightly longer timescale. In 1983 the Region adopted a 'dowry' funding policy whereby the health districts served by Darenth Park received an annual sum of revenue per resident discharged from the hospital. Central NHS resources had funded the hospital and local areas, not surprisingly, had been unwilling to fund care for people who had not previously been their financial responsibility. The dowry money represented 'new' money to fund ex-residents' care. The accompanying national regulations allowed transfer of these resources to other organisations thus giving local authorities and voluntary organisations an incentive to provide care for ex-Darenth Park residents. Darenth Park finally closed in August 1988 with most of the service development having taken place in the last five years.

Given the historical and enduring difficulties experienced by mental health, intellectual disability and other services for disabled people in securing adequate resources in most countries, the strategy of separate or protected funding has often been advocated. Are these services better off if their budgets are entirely separated from mainstream health or social care, or are they better if integrated into the mainstream?

Consider the case of services for people with mental health needs. Integration brings advantages. It is administratively simpler. It might also encourage multi-professional decision-making and working, because mental health specialists and other health professionals are part of the same organisation or funded from the same budget. Of course, working in the same organisation is no guarantee of collaboration, but integrated budgets should reduce the disincentives for professionals to work together to address the broad needs of disabled people. Integration also helps to reduce the stigma of (in this example) mental illness, and the associated discrimination. Within an organisation, if budgets can be used flexibly, integration might encourage innovation, for example by putting greater emphasis on preventive activities and the treatment of co-morbid mental and physical health problems.

On the other hand, there is a chronic lack of awareness of mental health problems and their treatment among (mainstream) health system decision makers. Consequently, as part of an integrated system, mental health resources and priorities may be neither prioritised nor protected. A further disadvantage of integration is that there appear to be different need-generating factors for mental health compared to other health problems. This is the primary reason, for example, for the use of separate formulae for national allocations of mental health and other health funding in England. During the process of institutional closure, protection of a mental health budget might be essential for the success of an embryonic community-based care system. But this laudable aim needs to be distinguished from the argument that psychiatric inpatient facilities must not be closed because, with the danger of leakage of resources out of the mental health system, they offer the only recognisable and ring-fenced mental health resource.

In Germany, for many years the separate (supra-) regional funding of residential services encouraged local agencies to 'cost shunt', referring people to residential care rather than developing non-residential service options. Any separation (protection) of funding for one type of service runs the risk of creating perverse incentives.

There is no simple solution to the question of integration or separation, nor is there likely to be a single best arrangement that works across different countries or at different times in the redevelopment process. Different health and social care systems and contexts will probably need to take different decisions. Whatever the decision, there is obviously a need to create the right incentives for good joint working across services and agencies, as far as possible addressing the needs of disabled people holistically.

Centralised or devolved funding?

Budgeting responsibilities are held at different levels within a care system. Some are at a macro level – at the 'top' of a health or social care system, perhaps – and may be organised nationally or regionally, and some are delegated to local organisations, municipalities or individuals. The balance between macro and micro responsibilities depends on many things, including a country's constitutional structure and its broader policy stances with respect to devolved decision-making, accountability and user empowerment, and the perceived or achieved effectiveness of central policy levers and incentives. The relevance of this topic here is whether funding reaches services through some direct, top-down allocation – such as a centrally issued budget to a hospital in the form of a lump sum or an amount per occupied inpatient bed – or whether it is allocated to a local or regional body which then makes spending decisions. A further degree of devolution would be to pass funding responsibility to teams or individual professionals such as care managers or primary care doctors, as happens or is proposed in a small number of European health and social care systems.

In principle, devolved budgets and purchasing should increase the likelihood that decision-making is sensitive to user needs and preferences. Through their everyday work, service professionals are well placed to recognise individual and (local) community needs and wants. Devolving financial responsibilities to them or to local agencies could be seen as one way to encourage a care system to become more 'needs-led' or 'preference-led', although budget-holders would need to have the right information, skills, autonomy and incentives to work flexibly, effectively and efficiently. Devolved budget holders may have less information than a central budget holder, fewer technical resources to process what information they have, and less financial cushion in the event of mistaken decisions.

Decentralised decision-making therefore requires a well-planned budget allocation mechanism and robust accounting procedures. It is associated with greater financial risks, and may therefore encourage conservatism, with local purchasers avoiding untried (including innovative) care arrangements. In contrast, a centrally controlled budget allows risks to be pooled and spread, and gives greater purchasing power (to achieve better price deals). Centralised budgeting might also make it is easier to respond *strategically* to countrywide or area-wide needs. Centrally controlled decision-making should also iron out unevenness in access to services and the quality of provision, provided that appropriate and effective regulatory processes are in place, and hence could be better at protecting the rights of disabled people.

With different levels of budgeting responsibility there are different incentives. With a highly centralised budget there might be few incentives for local bodies or individual professionals to seek efficiency-improving arrangements: an efficiency saving this year might only be rewarded with a budget cut next year.

Allocation mechanisms

Formulae will be needed to distribute budgets to local bodies under a devolved funding system, or to individual providers (such as hospitals) under a centralised system. Ideally, those formulae would reflect the distribution of needs and agreed policy priorities. There are basically four mechanisms by which resources may be allocated to service purchasers in fixed budget systems[162]:

- based on size of bids from purchasers
- political negotiation
- historical precedent
- independent measurement of health care needs.

The first three options do not provide incentives to improve overall equity and efficiency in the delivery of mental health care services, or – in particular – to alter the balance of care, yet are still in widespread use. The fourth option would see resources allocated using a needs-based capitation formula, taking account of the socio-demographic make up of local populations, social deprivation, morbidity and cost variations (as in the Swedish and English health systems, for example). Devising an allocation formula is not straightforward, and there are other complications to take on board not discussed here. The main point to emphasise, however, is that a devolved budget, with associated freedom for budget holders to spend the funds with some flexibility increases the likelihood that services will be purchased in response to the assessed needs and expressed preferences of individuals, and should also increase the likelihood that the balance of care will shift away from reliance on institution-dominated models.

Commissioning

Commissioning comprises a number of tasks or stages (from Knapp *et al*[90]:

- Development and agreement of a mission or set of objectives.
- Assessment of the needs of the population.
- Location, assessment, development or stimulation of the services that the planning activity suggests are needed, through contacts with current and potential providers.
- Service specification.
- Contract agreement with providers.
- Performance review, both formally through monitoring procedures embodied in contracts, and informally.
- Contract renewal or termination.
- Information feedback to the beginning of the sequence about needs, both met and unmet.

Commissioning choices have consequences for the way resources are deployed, and ultimately therefore for the costs, outcomes and cost-effectiveness of a care system. For example, in Russia hospitals with more than 1000 beds are more generously financed than smaller hospitals, and the general funding environment provides incentives to keep institutions full[163]. Short-term contracts with independent sector providers give commissioners a lot of flexibility but make it hard for providers to plan for the longer term by, for example, investing in staff or capital development.

Clearly the commissioning culture within a care system will have implications for the services that are delivered. Are there long-term relations between the agency that holds the budget and service providers, or only shorter-term links? Are relations robust (based on explicit arms-length contracts) or 'cosy' (based on implicit informal funding transfers)? Do they encourage market-like competition for contracts among providers, or a more hierarchical model of command and control? Are relations broadly 'adversarial', based on threat, or more 'obligational', based on trust? What form do contracts take – large block purchasing arrangements or individually responsive 'spot' purchasing models? Do they incorporate performance requirements, such as achievement of a particular portfolio of services or quality of care? What monitoring requirements are set, to check on performance and contract compliance, and how much do they divert resources away from actual service delivery?

Even though some commissioning arrangements would be expected *a priori* to work better than others, there is no simple blueprint for success. In particular, there is widespread discussion about the comparative merits of market-driven versus hierarchical structures, but this is an area beyond the scope of the present report. (An earlier account of the development of social care markets in England included a detailed analysis of market structure and incentives, contract types and pricing; see Wistow *et al*[164] chapters 7 and 8. More recent experiences are described in Netten *et al*[165]). What proves to be appropriate for commissioning residential services in one system may not work for day activity services in another. Local decision makers will need to respond to local circumstances and preferences in pursuit of locally relevant goals.

Consumer-directed care

A trend in some countries is the development of self-directed (or consumer-directed) care[73]. The primary aim is to give more independence and choice to people, and thereby give them greater control over their lives. Person-centred planning is one such arrangement[166]. Voucher-like arrangements are also being used. An increasingly popular model to explore is to hand funding over to individuals to purchase their own care. This has been an important principle of the German long-term care insurance reform, and in England with the (patchy) development of direct payments[167] and the piloting of individual budgets[69]. There are few examples of this degree of devolution of funding responsibility in Italy.

There are a number of arguments for these kinds of initiative, most strongly that they emphasise independence and empowerment. There is also a belief that such arrangements can improve quality of care while being cost-effective, although the necessary evidence has yet to be assembled. The approach appeals both to the political Right because it hints at market-like mechanisms, but also to the Centre Left because of its encouragement of individual choice and public service accountability. From the user perspective, self-directed services can be attractive because of the empowerment offered, and are clearly consistent with a rights-based agenda. They could also help to break down barriers between services, sectors and budgets, because funding can be used across and between conventional fields such as health, social care and housing.

On the other hand, self-directed arrangements place considerable responsibility for finding, monitoring and purchasing services on the shoulders of individual users or their families (if indeed the latter are available to help)[40]. The funding transferred to individuals might be too little to allow them to access services they want or feel they need. Individual purchasers will have little bargaining power relative to service providers (compared to, say, large purchasers such as a municipality or social insurance fund), and there is the risk of exploitation by providers or 'financial advisers'. Although brokerage (advisory, support) services are usually established in self-directed care systems, coverage or quality might not be adequate: good expert support is essential. And, of course, if the right services are not available for individuals to purchase, then a system of self-directed care could be highly constrained.

Multiple funding sources

Multiple needs

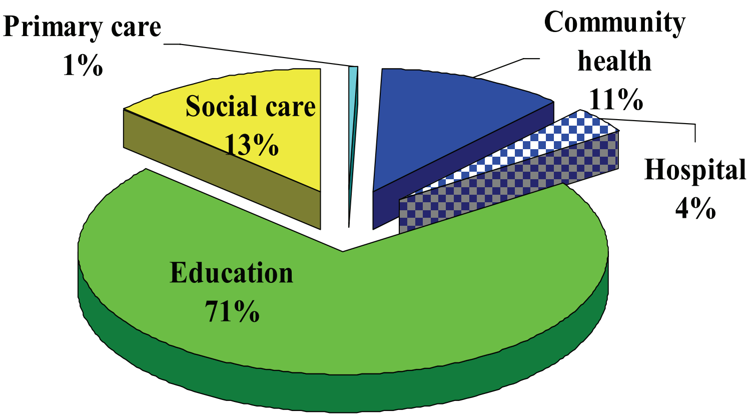
As noted on page 44, it is not unusual for someone with a long-term disability or health problem to have needs for support across multiple life domains. There are likely to include health needs, but also support might be required in finding or retaining paid employment. If they are not working they will probably qualify for social security support. Social care agencies might be involved in providing accommodation or home-based services or equipment. There may be a need for housing adaptations or simply access to social housing. Family carers might have needs because of the burden of providing informal care. In extreme cases, some people with behavioural problems might - through desperation or victimisation – have higher-than-average contacts with the criminal justice system.

As a care system shifts the balance of care away from institutions towards community-based arrangements, so too will the balance of funding need to shift from almost exclusive reliance on health systems (indeed on a single, consolidated institution budget) to a mixed economy of services that draw their resources from a potentially wide range of budgets. A considerable challenge will be the coordination of multiple funding sources, with all the various organisational and inter-professional interfaces and incentives that accompany them. People who move out of long-stay hospital accommodation are still going to need access to backup services, which may include the occasional in-patient psychiatric admission, so management of the hospital-community interface is among the challenges.

Multiple costs

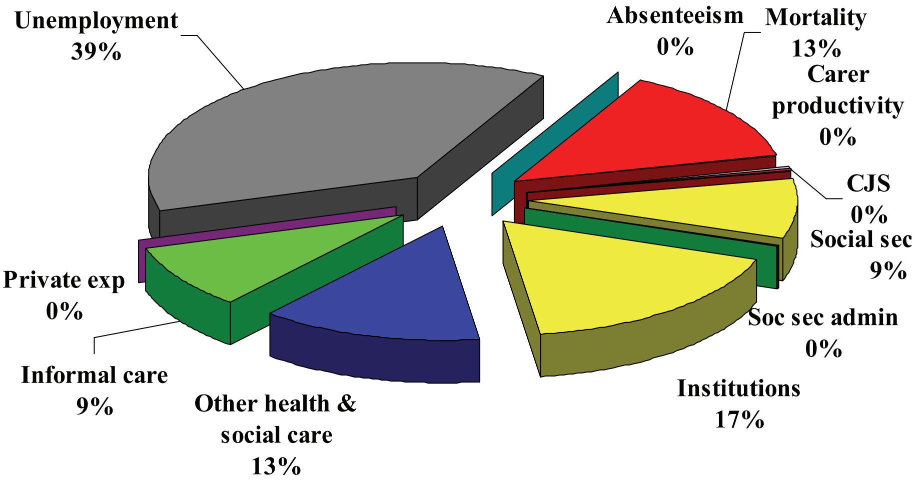
Many examples could be offered of these multiple needs and multiple responses. The range of services used by former hospital residents has already been illustrated in Table 11 and provided case study examples in Table 13 and Table 14. Two further illustrations are given in Figure 4 and Figure 5, again drawn from English studies[168,169].

Figure 4 Costs of services for children with severe intellectual disabilities



Total cost for just these services averaged £15,700 per child per year, at 1997/98 prices

Figure 5 Costs for people with schizophrenia



Average cost = £54, 596 per person year (England 2005)

The first of these (Figure 4) summarises the service costs of supporting children with severe intellectual disabilities, showing the high involvement of education, social care and health services[168]. The second (Figure 5) focuses on people with schizophrenia, and shows the range of agency costs, the imputed costs informal care, and a monetary estimate of the impact of schizophrenia on employment and hence on productivity[169]. Similar pictures, although with slightly different percentage contributions, have been painted for Italy (eg Tarricone *et al*[170] and Germany (eg Rössler *et al*[171]). The breadth of service impacts and the important contributions to total cost of lost employment and carer time appear to be international phenomena.

These and many other studies like them demonstrate the breadth of economic impact. A study of children with persistent antisocial behaviour in London[172] found that only 5% of the total cost was carried by the health service, the remainder falling to schools (special educational needs), social care agencies, community voluntary organizations, families (disrupted parental employment, household damage) and the welfare system (disability and similar transfer payments). An earlier study found that adults who, as children, had a conduct disorder generated costs for a range of agencies that were significantly higher than the costs for a non-morbid control group; most noticeable were the criminal justice system costs, which were 18 times greater[173]. Needs in old age can similarly impact on a range of services and budgets. The recently published *Dementia UK* report[174] estimated that the total costs of dementia today amounted to £17 billion, with accommodation accounting for 41% of the total, health services 8%, social care services 15%, and imputed costs for informal care support and lost employment 36%.

Service use patterns and therefore also cost patterns will vary considerably from country to country. Two multi-country European studies of people with schizophrenia provide illustrations. The EPSILON study[175] demonstrated how service systems and availability varied greatly between Italy, Spain, the Netherlands, Denmark and England. The ERGOS study[176] similarly found distinct differences in patterns of treatment and care across countries.

Not surprisingly, many coordination problems can emerge, linked most noticeably to differences in entitlements and access, and the (sometimes perverse) incentives created in those care systems that have followed more of a 'managerialist' approach built on performance targets. The root problem is the fragmentation of decision-making and the barriers erected by 'silo' budgets. Box 4 describes the example of the 'delayed discharge' of older people from hospital in England, which shows how problems of coordination cause inefficient use of resources and poorer results for people using services. Wasteful overlaps between services and – more commonly – wide gaps in the spectrum of support could be the result: there is a danger that people 'fall through the net' of support.

Setting a performance target (closing a certain number of hospital beds, developing a certain number of community services) can clearly be a facilitator in changing the balance of care: performance targets are often an integral part or inevitable corollary of a local plan or a national strategy. On the other hand, a narrowly defined performance target can create disincentives for an agency to take decisions which are in the wider interest, simply because they are driven by self-interest – indeed forced to behave in such a way by the performance assessment regime. Professional rivalry, myopic budget protection, ignorance, indifference or simply stultifying bureaucracy could also mean one agency being unwilling or unable to spend more of its own resources in order for another agency to achieve savings or for the broader system to achieve better outcomes. This is linked to the widely recognised challenge of silo budgets: funds earmarked for one use are not transferable to another.

Box 4 'Delayed discharge' from hospital for older people in England

There has long been a perceived problem of older people accommodated in acute hospital beds long after their immediate health needs have been met. The Department of Health in England responded to this growing challenge by announcing the National Beds Inquiry (NBI) in 1998 to 'review assumptions about growth in the volume of general and acute hospital services and their implications for health services and hospital bed numbers looking 10 to 20 years ahead'. A literature review commissioned by the Inquiry concluded that 20% of hospital inpatient bed days accounted for by older people were probably inappropriate due to the absence of alternative service arrangements[177]. The Inquiry stressed that hospital services need to be considered in a wider context, including other parts of health and social care systems.

Local authorities (which have responsibility for social care) and now charged by the health service for the costs of older people remaining 'unnecessarily' in hospital beds once their immediate health care needs have been met.

This finding was corroborated by Fernandez and Forder[178] who found that provision of social care services (both community- and institution-based) significantly reduced delayed discharge rates. Local resource levels and input prices mattered: other things being equal, richer authorities and those facing lower input prices (lower property prices and wages) enjoyed significantly lower delayed discharge rates, and generally much of the variation in delay rates could be linked to factors outside local authority control. Other research has shown that poor discharge planning was a major factor in delayed discharge. In other work to be published shortly, Fernandez and Forder have shown that transferring some funding from health to social care budgets would have a positive net benefit in terms of the costs of supporting older people and the (health-related and welfare-related) quality of life outcomes achieved.

If the shift from institution to community brings a change in responsibility for funding and organising care, then there is a chance that different entitlement criteria may come into play, so altering access. In England, for example, the universality and solidarity that characterise the National Health System contrast with the selectivity, eligibility thresholds and means testing that characterise social care. This has led to numerous difficulties for people with dementia and their families as the locus of care has moved from hospital wards (free at the point of use) to nursing or residential care homes (for which users will be charged if their assets are in excess of a relatively modest amount. In Germany, only the medical aspects of psychosocial care are covered by the social health insurance system, and long-term care needs for people with enduring mental health problems are seen as social rehabilitation or reintegration and are therefore the responsibility of social welfare agencies, which are tax-financed and which may charge users or their families. The German health and social care system has long been more highly fragmented than in England, with the added challenge of an absence of central strategic control or influence from government[179] (and see the German country report in Volume 3). Affordability can become an issue, and use of services may be suppressed to the detriment of quality of life and long-term health.

System and service fragmentation also characterise Italian care systems. For example, Fattore *et al*[180] describe mental health care in Lombardy, and in particular the multiple costs of support for many people, particularly those with severe and enduring needs. The authors express concern that the introduction of a fee-for-service arrangement for financing services will work against integration, and so work against what should be one of the fundamental aims of community-based care.

Coordinating care across a complex multiple-service, multiple-budget world is one of the biggest (and generally unsolved) mysteries of community care systems across Europe. Many efforts have been made, including:

- setting up agreements that tie in relevant organisations in the state and voluntary sectors (and ideally also the private sector) to a shared plan for action
- designating one organisation (say the municipality or the primary health care service) as the ‘lead agency’ with responsibility for strategic coordination in a particular field
- creating ‘street-level bureaucrats’ in the form of case/care managers or other ‘care brokers’ to assess needs and coordinate service responses
- seeking to reach agreements to facilitate the movement of money between different national or local budgets in order to help overcome some of the disincentives that distort or inhibit appropriate action
- more radically, establishing joint budgets across health, social care, housing or other agencies from which jointly to commission services
- self-directed care arrangements of the kind discussed in section 10 - devolving responsibilities for assessment and purchasing to individual users or families would be expected to help overcome these difficulties, provided there was sufficient support.

6. The dynamics of change

On page 59 four questions relating to costs, needs and outcomes were set out that need to be addressed when looking at the consequences of – or indeed some of the arguments for and against – shifting the balance of care from institutions to services in the community. Those questions and the circumstances they described were essentially static: they described costs and outcomes by comparing the situation before and after change had occurred. It is important, however, to examine the situation during the process of change, moving from the static to the dynamic. A number of elements need to be considered, particularly what happens to costs as institutions run down to closure and as community-based services are developed. These dynamic experiences can lead to reactions that can erect barriers in the way of more effective and cost-effective systems of care. By definition, these are barriers that do not exist at the start of the process, but emerge as it gets underway.

Questions about dynamics

To follow on from the four empirical questions given above, three more questions need to be answered as the process of change occurs. Given that it can take many years to close a large institution such as a psychiatric hospital, these dynamic questions are of some relevance.

Question E: How does the expected cost of care in the community for people currently in institutional care compare with the cost of community care for people currently in the community?

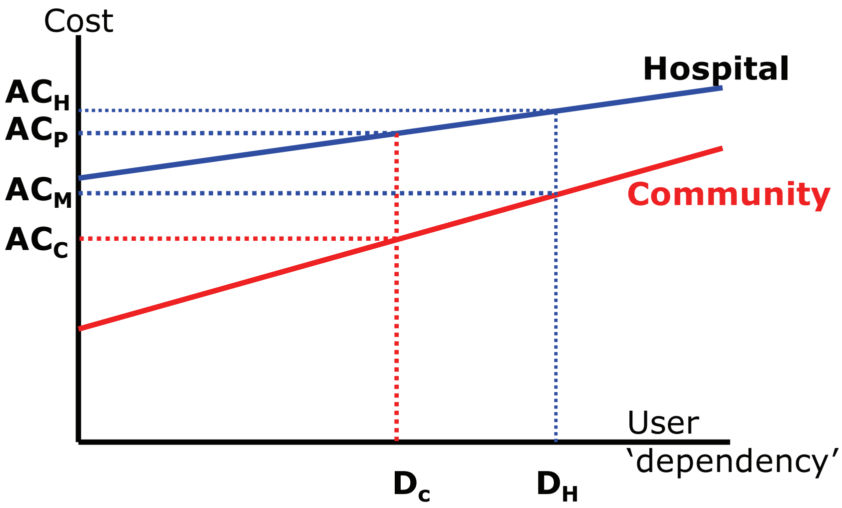
Question F: How does the expected cost of care in the community for people currently in institutional care compare with the cost of their current hospital care?

Question G: As the balance of provision shifts from institutional to community care, what happens to average cost in each setting?

Again, these questions can be illustrated by reference to a diagram, reproduced as Figure 6.

As the diagram is drawn, if someone with the mean level of disability for people in the institution (in this case in a hospital) – which is indicated in the diagram by D_H – moves to the community, the cost of their care will fall (from AC_H to AC_M), which is the (conjectured) answer to question F. At the same time, however, the community cost for this 'typical' hospital resident (AC_M) is higher than the currently observed average cost for people living in the community (AC_C), but the difference is not as large as the current difference between the two settings (which is indicated by the difference between AC_H and AC_C). In other words, someone moving from hospital is going to cost more to support in the community than people already living there. The answer to question E, therefore, has implications for the funding that decision makers ought to make available in order to support people making the move from one setting to another. But even though the cost of community care for people currently in hospital is higher than might have been expected from today's costs, this conjectured answer to question E asserts that there would still be a cost saving as a result of the move.

Figure 6 Costs and disability as the balance of care changes



Finally, if a hospital closure programme not only relocates the 'easiest' or less dependent hospital residents first (as suggested by previous research in the mental health and intellectual disability fields, as noted earlier), but also moves people who are more dependent than the community average (which would be illustrated on Figure 6 by the movement of someone with level of disability somewhere between D_C and D_H from hospital to community), the result will be that both average level of disability and the average cost will go up in *both* settings. This is our conjectured answer to question G. Note, however, that the total costs of care for the hospital and community groups combined – that is, for the whole system – will be lower.

The reason why these questions are relevant should therefore be plain. The changing costs (and, probably, the changing outcomes, although these are addressed here) as the process of changing the balance of care gets underway could give the wrong signals. The point in the last paragraph (in relation to question G) is that decision makers will see average per person cost going up in both hospital and in the community, which might be hard to comprehend if one of the assumptions or aims behind the deinstitutionalisation policy was to save money. Similarly, today's observed average costs (for example, for community care) do not tell us what the future such costs will be once there has been a relocation of people out of the institutional setting.

Is there evidence to answer questions E to G? Reliable evidence could only be found for England and Wales.

Evidence from mental health care in England and Wales

The previously cited English and Welsh study from the mid 1990s of almost 400 community accommodation facilities and psychiatric inpatient settings spread across eight localities provides us with some answers[83]. In five of the eight areas it was found that it would cost more to provide community care for people moving from hospital than it was currently costing to support the community care sample. Consequently, a decision maker seeking to resettle the 'typical' hospital inpatient (the person with the mean level of disability in the hospital) will have to find funding, not at the level AC_C in Figure 6 (which was equal to £342 in one of the study areas at the time, for example – in mid 1990s prices), but the significantly larger sum AC_M (which was equal to £396 in that same area at that time). This answer to question E, in these five localities at least, means that the savings of a hospital closure programme would be exaggerated by currently observed average costs. There is consequently a danger that new community placements would be *under-funded* for the former hospital residents because community provision to date has been offered to people with fewer needs for support. In the other three localities of this old study, moving people from hospital to community residential accommodation would not have represented a significant change in the costs of their care.

The findings from this study also provide an answer to question F. The predicted cost of care in the community for people currently in hospital (denoted AC_M in Figure 6) was found to be significantly lower than the cost of their current hospital care (AC_H) in all eight localities. Considerable savings could therefore be reaped by shifting the balance from hospital to community care for those people covered by this study. The observed average weekly difference in cost between the two settings was £518 in London, for example. This difference arose partly because of a difference in level of disability/need between the settings, but mainly because hospitals appeared to be intrinsically more expensive than community settings. Outside London, the observed average weekly cost difference was slightly lower (£403 at the time) and was again mainly attributable to intrinsic cost differences between hospital and community care. This reinforces what was said earlier – funds could apparently be saved if people inappropriately accommodated in hospital were to move to community residential facilities.

It was not possible to address question G directly with this study, as it only collected cross-sectional data. Nationally, average per person costs adjusted for input price inflation (so-called ‘real costs’) have grown over time, which offers some evidence. The point is that early successes in moving people from hospital to community (which can be achieved by moving the least disabled, most independent people first) will usually offer encouraging evidence of success, but it could prove harder to achieve similar successes as more disabled people move. Moreover, because average costs are likely to change as the closure process gets underway, decision makers might be alarmed by the escalating costs, which could be a barrier if they are not aware of the broader picture. This reinforces the need for a well-developed, long-term plan for changing the balance of care. It also suggests caution in transferring funds from an institution to the community. If an institutional closure plan means moving the most able residents out first (the people whose skills, abilities and behavioural characteristics are best suited for a more independent life in the community), it would be wrong to transfer the average amount from the institutional budget to community services, because this would stripping the institution of resources.

If institutional costs rise over time, then decision makers also have to be careful about being over-cautious at the outset of the transition process. Dissatisfaction with quality of care in institutions leads to rising costs in institutions over time. For example, the *per diem* costs of public residential institutions for people with intellectual disabilities in the USA, after adjustment for inflation, more than doubled between 1982 and 2002[181]. Costs rise because less disabled people are often provided with alternative services first (so the population in institutions includes progressively the most disabled); because more staff are employed in the institutions; and because fewer residents live there in order to try to provide higher quality care. Therefore, cost comparisons that seem to make institutional care less expensive than community care today cannot be sustained in the medium term.

A related issue is the dynamic of change for individual staff members. When hospital closure is announced it is often the most useful staff who leave first, taking with them many of the most important skills from the institution. Replacing such staff in an institution that is planned for closure is not going to be easy. If the most able (least disabled) hospital residents also move out first, then the hospital is left with (on average) poorer quality staff and more disabled residents, which could be a major challenge.

A rather different dynamic is the tendency in some countries, including in central/eastern Europe, to hold onto the most independent or able institution residents as closure gets underway because they are valued as a source of free labour. In those settings, the dynamics are therefore rather different.

Generally, these complicated dynamics emphasise the need for long-term plans for closing an institution – the need for an accurate and realistic needs assessment for the whole institutional population (ideally assessing needs as they will likely manifest themselves in the community, rather than needs as displayed in the hospital) and the associated cost implications.

7. Conclusions and Recommendations

This section of the report summarises the conclusions of the study, starting with the conclusions and recommendations drawn from the review of existing information and then presenting the conclusions drawn from the analysis of the process, costs and outcomes of developing effective services in the community to replace institutions. Finally, this section presents recommendations for how governments can take forward this agenda for change.

Review of existing sources of information

Article 31 of the UN Convention on the Rights of Persons with Disabilities requires States to collect data 'to enable them to formulate and implement policies to give effect to the present Convention'. Such information 'shall be disaggregated as appropriate' and used to address the barriers faced by disabled people in exercising their rights. States 'shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others'.

It is clear that the countries taking part in this study have some way to go to meet this requirement. At present, comprehensive information is not available for all types of residential services provided nor for all the client groups involved, nor is there clarity about the definition of kinds and characteristics of services provided or people served. Where such information exists, it is not always collated at national level. The data presented here form a starting point – both in terms of specifying what is currently available and in terms of estimating the numbers of disabled people in residential care – on which future efforts will have to build to enable countries to fulfil their obligations.

Recommendations

1. *Agree a harmonised data set at European level*
    - 1.1 The European Commission should promote joint work between Member States and Eurostat to define a minimum data set for residential services (defined broadly) for people with disabilities.

    - 1.2 The data set needs to include information that will permit the review of Member States' progress in the closure of institutions and of the growth of independent living and services in the community.

    - 1.3 The data set needs to be workable both for countries which still have services largely based in institutions, where the distinction between institutional care and care at home is very clear, and for countries which are in the advanced stages of replacing institutions with community-based services and independent living. This is likely to require a combination of information about numbers of places in services (eg how many places are there in residential establishments where more than 30 people live, of whom at least 80% are mentally or physically disabled?) with information about people (eg how many people live in a house or apartment they own or rent, with what amount of staff support each week?).

1.4 The data set needs to include sufficient information about the people served (gender, ethnicity, primary disability) to enable States to ensure that everyone is benefiting from the transition away from institutions to better alternatives in the community.

2. *Publish statistics demonstrating progress in each country*

2.1 The European Commission should work with Eurostat towards the regular publication of statistics demonstrating progress in each country in the transition away from institutions to better alternatives in the community. These statistics should be available on the world-wide web and should be freely available to disabled people, other members of the public, disabled people, non-governmental organisations and governmental organisations, so that they may use them in commenting upon and assisting in the development of better services.

2.2 The publication of statistics should be accompanied by an assessment by Eurostat of their accuracy and completeness for each country.

2.3 The Commission should work with Member States to identify a single source of information at national level in each country, competent to provide the information needed for the minimum data set and should promote the publication in print and on the world-wide web of the information available for each country.

The change process in three countries

Perhaps the most striking characteristic of the process of service development in the three countries studied in depth is the importance of coordination of different agencies involved in the transition process. The number of agencies involved, their geographical spread and the involvement of different tiers of government all make good coordination essential. It is simply not feasible to leave to the institution, or the local authorities involved, the task of dismantling institutions which serve people from many different municipalities. Regional and national governments have an important role in driving the process forward, both through their own actions in setting the legal and policy context and through the way they construct and manage the framework of incentives.

Creating new roles for actors in the process is also a major part of the transition task. Traditional service providers – organisations and the people who work in them – need to be offered new roles, either in providing modern services in the community or through leaving the provision of care. New actors – organisations of service users and their families, non-governmental organisations wanting to be involved in providing new models of service, public authorities who have not hitherto played a role in helping their disabled citizens – also need to be involved.

The difference in pace between Germany on the one hand and England and Italy on the other seems to have been influenced by the depth of dissatisfaction among decision-makers with institutions. In both Italy and England, the vision of alternatives and the revelation of very poor conditions in institutions was clearly influential in the transition process.

Finally, England and Germany illustrate an important reason to involve disabled people in the process of service development and to listen and respond to their views and wishes. Service-led reform in these countries has essentially involved redesigning existing service structures to humanise them – replacing institutions with group homes, for example. Disabled people, once given the chance, identified and pursued the considerably more ambitious goal of independent or supported living, organised as 'self-directed services' using individual budgets. Service-providing agencies on their own are likely to be constrained by their past and present ways of thinking and working; the new models of service require a partnership between disabled people (and those who help and represent them) and agencies planning and providing services.

Cost-effectiveness of community versus institutional models of residential care and change over time

System structures

There are four main things to remember about care system structures to take forward into planning the transition from institutional models of care to services in the community:

- Most support for disabled people comes from families, friends and neighbours, but the inputs, responsibilities and burdens of family and other unpaid carers often go unrecognised and unsupported. If family care is not available, then paid staff will need to be employed at greater direct cost to the care system. There are however well known constraints on the availability of family carers (see below).
- The needs of disabled people often span more than one care or service 'system', and consequently many different agencies or sectors can be involved in community-based care, including health, social care, housing, education, employment, transport, leisure, criminal justice and social security.
- There are different ways to raise the finances that will fund these services, including through taxes, social insurance (linked to employment), voluntary insurance (at the discretion of the individual or family) and out-of-pocket payments by service users and their families. Most countries have a mix of arrangements, which can lead to difficulties because of the incentives and disincentives they can create.
- The complex context of most care systems (multiple services, multiple agencies, multiple funding sources and routes) generally means that there are no simple financial 'levers' to pull to bring about wholesale changes in service delivery.

Policies and plans

Closing institutions would be more straightforward if one had little concern for what happens to residents. The challenge is to build good services in the community and, as noted in reviewing transition in England, Germany and Italy, this implies the need for coordination and planning.

- Ideally, the transition from institutions to services in the community will have a national mandate. At the very least, there need to be local agreements between all potential service provider sectors. This plan should not just specify that an institution will close and indicate the target date, but should also include a detailed vision of the future care system. Consultation should be wide, and users and families should be involved throughout.

- The local plan needs to be based on relevant knowledge and robust evidence. Decision makers should understand not only which care arrangements and treatment interventions are effective and what they cost (and to which budgets), but also which are cost-effective.
- Carrying out a good cost-effectiveness analysis or other economic evaluation – to inform national policy or local plans – can be expensive and time-consuming. However, much can be gleaned from previously completed analyses if carefully interpreted in the local system context. It is important to understand *for whom* is a particular service or intervention likely to be cost-effective. For example, is cost-effectiveness achieved only for the health service and at the expense of higher costs for another agency? If so, this could put barriers in the way of system-wide improvements.

Costs, needs and outcomes

The (complex) links between costs, needs and outcomes sit at the heart of the evidence base on which to build a strong economic case for making the transition from institutions to services in the community.

- In a good care system, the costs of supporting people with substantial disabilities are usually high, *wherever* those people live. Policy makers must not expect costs to be low in community settings, even if the institutional services they are intended to replace appear to be inexpensive. Low-cost institutional services are almost always delivering low-quality 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.
- Costs in the community range widely – over many service areas and policy domains – in response to the multiple needs of individual disabled people. Families can also carry quite a high cost responsibility. It is therefore important to ensure that all local stakeholders are aware of, and obviously preferably agree with, the policy or plan.
- Costs are incurred to provide services, in response to needs, and in order to achieve outcomes. It therefore makes little sense to compare costs between two service systems without also looking at the needs of the individuals and the outcomes they experience.
- People’s needs, preferences and circumstances vary, and so their service requirements will also vary. Consequently, costs are unlikely to be the same across a group of people. This has at least two crucial implications. First, from a methodological point of view, comparing costs between two settings or service arrangements should be undertaken carefully unless it is known that the people supported in those different settings are identical in all relevant (cost-raising) respects, or that statistical adjustments are made to achieve equivalence. Not to do so risks dangerous under-funding of provision.
- Individuals’ needs change over time, especially in the initial few months after moving from an institution to a community placement. Service systems need to be able to respond flexibly to these changing needs. A linked requirement is for care systems to be able to respond to changing preferences, as long-term residents of

institutions will have little experience at the time they move out on which to form preferences about their lives in the community.

- The second implication of this inherent variation is that it opens up the possibility for purposive targeting of services on needs in order to enhance the overall ability of a care system to improve the well being of disabled people from fixed volumes of resources.
- Usually it is relevant to consider a range of outcome dimensions: not just symptoms (for people with mental health needs) or personal independence (for people with intellectual disabilities) for example, but also whether a changing care system improves an individual's ability to function (for example to get back to work or to build social networks) and their broader quality of life. It is generally the case that spending more on the support of disabled people will lead to better outcomes, but the relationship is not simple and decision makers may need to think carefully (and together with disabled people) about which outcomes they wish to prioritise within the care system.
- A new care arrangement (such as community-based care) could be more expensive than the arrangement it is replacing (such as long-stay hospital provision) but still be more cost-effective because it leads to better outcomes for service users and perhaps also for their families, and those improved outcomes are valued sufficiently highly to justify the higher expenditure.

For decision-makers contemplating a policy of changing from institutions to services in the community, some key effects are summarised in Figure 7. If existing institutional care is relatively less expensive, decision-makers can expect that transfer of the less disabled residents to good services in the community will be achieved at the same or lower costs and at the same or higher quality; cost-effectiveness in the community will be the same or better. More disabled residents in less expensive institutions will cost more in good community services but the quality will be higher and so cost-effectiveness in the community will be the same or better (and decision-makers should not assume that they can keep institutional costs low – see page 92).

Figure 7 Effect on costs and quality of transfer to good services in the community

	After transition to services in the community		
	Costs	**Quality**	**Cost-effectiveness**
Less expensive institution			
Less disabled person ➔	**Same or lower**	**Same or higher**	**Same or better**
More disabled person ➔	**Higher**	**Higher**	**Same or better**
More expensive institution			
Less disabled person ➔	**Lower**	**Same or higher**	**Better**
More disabled person ➔	**Same or lower**	**Higher**	**Better**

In more expensive institutions, decision-makers can expect that transfer of the less disabled residents to good services in the community will be achieved at lower costs and at the same or higher quality; cost-effectiveness in the community will therefore be better. More disabled residents in more expensive institutions will cost the same in good community services but the quality will be higher and so cost-effectiveness in the community will be better.

Supply constraints

- Family care may not be readily available to support people with disabilities. This could be because they have lost contact during the period of institutional residence. Or it could be because the burden of unpaid family informal care is too great. Unsupported family carers can experience many adverse consequences, including disrupted employment and lost income, out-of-pocket expenses, poor health and stress.
- Support can be provided to families in various ways, including through direct or indirect financial support, employment-friendly policies, educational programmes, counselling and respite services. These can help to reduce carer burden and make it more likely that disabled people can be supported by their families, if this is what they wish.
- A commonly found barrier to the development of community-based care systems is a shortage of suitably skilled staff. Transferring staff from institutions to the community is a possibility, but not everyone wants to make the move and these might not be the right people anyway.
- Paying higher salaries to attract better community care staff is one way to address shortages but obviously pushes up overall costs.
- Recruiting and training staff for community services needs to be done *before* disabled people start to move out of the institutions. The planning of future human resource needs should obviously be a key part of any local plan and national policy.

Local economic development

- Closing a large institution could have a major impact on local employment patterns if it is the only or main local employer. Building community accommodation for disabled people in the same communities in order to offer replacement work might not be a sensible option. Residents of the institution may come from other parts of the country and may wish to return to their local community. Local economic development considerations will need to be taken into account.

Opportunity costs of capital

- Many of today's institutions have low value in alternative uses because the buildings are old or in disrepair, and because the land on which they are located is not in high demand for redevelopment. Closing an institution might not therefore generate much additional money for ploughing into the necessary capital investment for community services.
- Even when a building or site has high economic value in alternative uses, the proceeds from their sale will generally not be realised until the institution has completely closed down. Consequently, some 'hump' costs will be needed – funds made available quite early for investment in new community facilities to get them underway. Double running costs will also be needed to resource both the old and the new services in parallel for a few years until the institution has fully closed down

Funding flows

- Concerns about the loss of budgets/resources into other parts of the care system or elsewhere following closure of an institution might be addressed by partial or temporary ring-fencing. Thus, for example, the budget currently allocated to a psychiatric hospital might be protected for the development of community-based services for people with mental health needs. Protection of this kind can provide protection and stability, and may help to 'kick-start' a new care initiative.
- Centralised budgets may be better vehicles for implementing national policies or priorities, but devolved budgets make it easier for local needs and preferences to shape local services. In turn this could make it easier to alter the balance of care away from institutionally oriented services and in favour of community care.
- Funding tied to individuals rather than institutions would help to break down one of the barriers to shifting the balance of care away from inpatient services.
- The commissioning environment – the way that services get procured – will have a substantial influence over the performance of a care system, including the balance of care. Decision-makers need to choose the style of commissioning carefully so as to create the appropriate incentives for improvement.
- Major year-on-year changes in budgets should be avoided, because they can be so disruptive. On the other hand, it may be necessary to move away from a gradual, *incremental* approach to change in order to challenge the status quo.

Multiple funding sources

- Because many disabled people have multiple needs, they may require or request support in the community from a range of different services, perhaps delivered by different agencies out of different budgets. This multiplicity must be recognised. The inter-connections (actual or potential) between services and agencies could put up substantial barriers to effective and cost-effective care.
- Joint planning and joint commissioning are among the approaches that can be used in an attempt to bring two or more budget-holding agencies together to improve service coordination and its impacts.
- Devolving certain powers and responsibilities to case/care managers, or even to individual service users via self-directed care arrangements, might also help overcome these difficulties.

Dynamics of change

- The dynamics of change are complex and can send out misleading signals about changing costs and outcomes. Decision makers must ensure that they take the long view.

Recommendations

These conclusions imply a central role for vision and leadership by national and regional governments, working in close collaboration with representatives of users and their families. They imply the need for a comprehensive, long-term perspective, which considers all the costs and all the benefits of the process of transition. They underline the need for creativity in developing solutions to the wide range of implementation problems which may emerge and learning from the process as experience and knowledge are gained of how to provide good services in the community. They also confirm that the available evidence is that, once comparison is made on the basis of comparable needs of residents and comparable quality of care, there is no basis for believing that services in the community will be inherently more expensive than institutions.

How can governments take forward this agenda? Change requires that governments, with other actors:

1. Strengthen the vision of new possibilities in the community
2. Sustain public dissatisfaction with current arrangements
3. Create some practical demonstrations of how things can be better
4. Reduce resistance to change by managing incentives for the different actors in the process

This list is not a sequence – attention needs to be given to each area throughout the process. Precisely what steps governments take, and the appropriate balance between different actions, will differ between countries depending on their circumstances. But these four issues will need to be addressed over the whole period of transition. Although other actors (for example, organisations of users and their families) will play an important role, the responsibility for planning, coordinating and managing the process will rest with governments.

The recommendations set out under each of these headings below are derived not only from the evidence presented in this report but also from the growing literature on modernising services for disabled people and from the authors' experience as actors in this field.

Strengthening the vision of new possibilities in the community

3. *Adopt policies in favour of inclusion*

3.1 Set out the goal that all disabled people should be included in society and that the help they receive should be based on the principles of respect for all individuals, choice and control over how they live their lives, full participation in society and support to maximise independence.

3.2 Commit to stop building new institutions or new buildings in existing institutions, and to spending the majority of available funds to develop services in the community.

3.3 Specify the overall timetable and plan for transition from institutions to services in the community.

4. *Develop legislative support for inclusion*

4.1 Adopt legislation that promotes independent living and social inclusion.

4.2 Ratify the UN Convention on the Rights of Persons with Disabilities.

4.3 Prohibit discrimination against disabled people in services and facilities.

4.4 Prohibit use of public monies to build new institutions.

4.5 Ensure that government agencies responsible for serving the population in a defined local area are made responsible for serving disabled people as well.

5. *Strengthen the voice of disabled people, families and their advocates in policy*
    - 5.1 Support groups that commit to inclusion and the replacement of institutions with community services.
    - 5.2 Appoint disabled people, family members and their advocates who are personally committed to inclusion to official bodies.
    - 5.3 Provide training for disabled people and their families in how policy-making works and how they can influence it.
    - 5.4 Require policy-makers and civil servants to regularly meet disabled people, family members and their advocates who are personally committed to inclusion and to identify how to strengthen their voice in policy.

6. *Require professional bodies to make their policies consistent with supporting inclusion*
    - 6.1 Require that bodies representing or training or accrediting the professional practice of personnel working with disabled people adopt a commitment to supporting the inclusion of disabled people in their work. This should include both specialist staff working with disabled people and others who may provide services to disabled people in the course of their work (eg police officers, nurses in general hospitals).
    - 6.2 Ensure that arrangements for training (including continuing professional development as well as initial training) and accreditation include disabled people and are based on the principle of inclusion.

7. *Encourage media interest in and support of inclusion*
    - 7.1 Promote the policy of replacing institutions with services in the community through official information and public education programmes.
    - 7.2 Help people providing good-quality services in the community and the people they serve to publicise their work.

8. *Learn from best practice in other countries*
    - 8.1 Support visits by disabled people, families, advocates, service providers and decision-makers to learn from good practice in community-based services in other countries, and reciprocal visits from those countries; instead of visits to and from providers of institutional care.
    - 8.2 Support participation in international networks (such as the European Coalition for Community Living) which will enable people to learn about best practice.
    - 8.3 Require that professional training for personnel working with disabled people includes the study of best practice in services in the community in other countries.

Sustaining public dissatisfaction with current institutional arrangements

9. *Open institutions to independent scrutiny*
    - 9.1 Require institutions to permit members of the public, non-governmental organisations and the media to visit them and to meet residents, families, advocates and staff who wish to do so.

9.2 Encourage institutions to promote their replacement with services in the community.

10. Create inspectorates to protect and promote the rights of individuals

10.1 Create inspectorates (which include disabled people and other ‘experts by experience’) to visit services, meet residents, families, advocates and staff and monitor their living conditions and quality of life
10.2 Publish the results of inspection visits.
10.3 Enforce the findings of these inspectorates where individuals require protection or redress.

11. Emphasise comparisons of quality of life

11.1 Encourage the description of living conditions and the quality of life of residents in institutions compared with (i) non-disabled members of the population and (ii) people of similar levels of disability receiving services in the community (elsewhere in the same country or in other countries); instead of the comparison with the same institutions in the past or with other institutions elsewhere.

Creating some practical demonstrations of how things can be better

12. Create innovative services

12.1 Fund the development of independent and supported living in the community, using ordinary housing and providing the level of staff support each individual needs.
12.2 Ensure that demonstration projects reflect best practice both in how they are set up and how they are run.
12.3 Ensure that demonstration projects both bring people back home from institutions and serve local people on ‘waiting lists’, so that members of the community in which services are developed are more likely to be supportive and helpful.
12.4 Ensure that demonstration projects include options both for accommodation and for occupation (education, employment or other day-time activities) to increase the likelihood of success.
12.5 Support new forms of training and professional qualification to ensure that there are sufficient staff to support people well as new services develop
12.6 Monitor the quality and costs of new services

13. Include everyone from the start

13.1 Ensure that schemes include people with more severe or complex disabilities early in the development process, so that experience of meeting their needs is gained from the outset.

Reducing resistance to change by managing incentives for different actors in the process

14. Create new funding opportunities

14.1 Set up mechanisms for individual budgets so that people can be supported to plan their new lives in a personally-tailored way

14.2 Create opportunities for new organisations to get involved in providing services in the community, outside the existing framework of institutional care, to pioneer the new models of support needed

14.3 Create financial incentives for local government to get involved in the inclusion of disabled people in their own community

15. Remove obstacles to development of services in the community

15.1 Create arrangements for contracting for innovative, local services, so that existing rules designed for institutional care systems are waived or modified to permit the development of services in the community.

15.2 Review rules for other relevant services such as planning, housing, employment, social security and health care to ensure that disabled people supported in the community can get equal access.

15.3 Work with the European Commission to ensure that EU rules on employment, health and safety and other areas of EU competence support rather than hinder the development of good services in the community.

16. Make funding of new services contingent on quality

16.1 Ensure that new services are only funded if they are of good quality, that quality is reviewed (using the experience of disabled people supported by the service as the primary measure of quality) and that funding is discontinued if services do not maintain acceptable standards.

16.2 Resist pressure to redevelop institutions or build new institutions as 'temporary' expedients.

16.3 International bodies, such as the World Bank and the European Commission, should not permit use of their funds to redevelop institutions or build new institutions.

Appendix 1
Composition of consortium

The consortium was drawn together to include partners each of whom possesses

- outstanding academic reputations for research on community living for people with disabilities, cost of institutional care and/or cross-national comparisons
- excellent links with service user and service provision organisations as well as with disability policy-makers
- a representation of relevant disciplines and a multi-disciplinary perspective

There were no financial or legal links between the partners.

The consortium was led by Prof Jim Mansell, Prof Martin Knapp and Dr Julie Beadle-Brown in a partnership between the University of Kent (Tizard Centre) and the London School of Economics (Personal Social Services Research Unit). Prof Mansell, Prof Knapp and Dr Beadle-Brown also acted as experts feeding into all three Phases of the project.

University of Kent, Tizard Centre

The Tizard Centre is one of the leading academic groups working in community care in the UK. It has contributed to the improvement of services for people with intellectual disabilities through research, through teaching professional staff and through consultancy with a wide range of relevant organisations. The Centre's work has had a substantial impact on policy and practice, especially in relation to deinstitutionalisation and community living, challenging behaviour, protection from abuse and quality of care.

Prof Jim Mansell is the Director of the Centre. He is a Chartered Psychologist and Fellow of the British Psychological Society with a background in social policy. He has been involved in the research and development of deinstitutionalisation and community living since 1970. He is a Trustee of a large national charity providing services for people with intellectual disabilities (United Response), a Commissioner for Social Care Inspection in England and a member of HM Government's Learning Disability Task Force. He has a longstanding interest in international comparison, editing the 1996 book *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA* and has current international collaborations with European and Australian partners.

Dr Julie Beadle-Brown is a Chartered Psychologist and a Senior Lecturer in Learning Disability with 10 years experience specialising in quality of care, early intervention and autism. With Prof Mansell she was responsible for setting up and co-ordinating the work of the *European Intellectual Disability Research Network* (funded under Framework 5) and for providing the research leadership in the *Included in Society* project coordinated by Inclusion Europe and funded by the European Commission. Dr Beadle-Brown has also managed four other projects in the last two years (on early intervention in autism, quality of care in community-based residential homes, national minimum standards for residential care and placement out-of-area of people with intellectual disabilities).

Also involved from the University of Kent have been Robert Hayward, research worker on the project and Agnes Kozma, PhD student.

London School of Economics, Personal Social Services Research Unit (PSSRU)

PSSRU was established more than 30 years ago to conduct studies of equity and efficiency in social care. PSSRU is now located at three universities in England. At the LSE, the PSSRU branch is part of LSE Health and Social Care (LSEHSC) and has close links with the European Observatory on Health Systems and Policies. The 45 staff in LSE Health and Social Care work across the areas of health and social care policy, particularly in European-wide studies. Recent research grants to PSSRU include the Mental Health Economics European Network with Phase 1 (2002) and Phase 2 (2005) both funded by the European Commission; OPTIWORK: Optimising Strategies for Integrating People with Disabilities into Work, also funded by European Commission in 2005; Individual placement and support to improve occupational outcomes for people with severe mental illness funded by the Wellcome Trust (2004); The evaluation of the impact of the direct payments implementation strategy in social care, funded by the Department of Health in 2004; and the economic evaluation in social welfare: further development of the infrastructure, funded by The Joseph Rowntree Foundation in 2002.

Prof Martin Knapp is an economist with 30 years of specialisation in the areas of social and health care, in the UK and in a number of other countries. He has held professorial positions at the LSE and the Institute of Psychiatry for more than ten years, and was previously based at the University of Kent. One of his current responsibilities is coordinating the Mental Health Economics European Network (MHEEN) which, in it second phase, is looking (*inter alia*) at the economic barriers to and opportunities for deinstitutionalisation within mental health services in 31 European countries.

Also involved from PSSRU have been Jennifer Beecham, David McDaid, Jose-Luis Fernandez and Tihana Matosevic.

The other partners in the consortium were:

University of Siegen, Centre for Planning and Evaluation of Social Services

The Centre for Planning and Evaluation of Social Services (ZPE) is an academic research centre at the University of Siegen where 8 professors and 32 research officers cooperate to support the modernisation of social services. The disciplines represented are sociology, social administration, social work, education, psychology and social medicine. The Centre works in close cooperation with social work organisations, administrations and ministries on a regional and a national level. The ZPE is also linked with other universities in different European countries through joint research projects including the European Intellectual Disability Research Network (IDRESNET) and the German Association for Evaluation (Deutsche

Gesellschaft für Evaluation). The ZPE also cooperates with universities in Porto Allegre, Novosibirsk and Minsk.

Dr Johannes Schädler is the Centre manager. He worked for the German national organisation for people with intellectual disabilities from 1988 to 1995. Since 1996 he has successfully coordinated projects on respite care (1997-1999) and on local disability planning. Since 2002 he has co-ordinated the European Intellectual Disability Research Network (IDRESNET).

Also involved from the University of Siegen have been Albrecht Rohrman and Anja Frindt.

Psicost Scientific Association, Jerez

Psicost Scientific Research Association is a Spanish non-profit national research association on service assessment and costs related to mental illness and intellectual disability. Six Spanish research centers including universities (Universidad de Cadiz, Universidad Autonoma de Madrid, Universidad de Granada, Universidad Publica de Navarra), management and other areas (Coorporació Sant Joan de Deu – Barcelona), cooperate with Psicost. The association has members working in intellectual disability, mental health, epidemiology, mental health economics and geography of services. It has participated in research projects funded by local, regional, national and international organisations, published handbooks and papers and organised workshops, postgraduate courses and national and international meetings on outcome research management and related areas.

Prof L Salvador-Carulla, MD, psychiatrist and Professor of Psychiatry in the University of Cadiz is the President of the Association. He is also President of the Section of Mental Retardation of the World Psychiatric Association, member of the European Association of Mental Health in Mental Retardation and of the Editorial Board of the Journal of Intellectual Disability Research and the Journal of Mental Health Economics and Policies.

The team at PSICOST has also included Rafael Martinez-Leal, M Poole, JA Salinas and A Romero.

Charles University of Prague, Faculty of Education

The Faculty of Education has been qualifying and training professionals for adult education and social services in the Czech Republic for decades. The Department of Special Education is responsible for study programmes as well as for research activities in the field of intellectual disability. Changes in politics and society in Central and Eastern Europe after year 1989 brought the necessity to create and evaluate new models for supporting people with intellectual disabilities within deinstitutionalisation process. Collaboration with other academic bodies through European research projects is an important step towards effective de-institutionalisation at national level.

Jan Siska, PhD has been a Senior Lecturer at the Department Of Special Education since 1997. He has been actively involved in the modernisation of social services and has extensive experience in working together on research projects with EU non-governmental organisations and research centres (Inclusion Europe, Open Society Institute) as well as with research centres from accession European countries.

The team managed by Jan Siska has included Jana Vránová (Czech Rebublic) and Barbara Vann (Romania, Hungary, Bulgaria and Poland).

European Association of Service Providers for Persons with Disabilities (EASPD) and *The Catholic University of Leuven, LUCAS*

These two organisations worked together to collect the data from Belgium, France, Luxembourg and the Netherlands. Their contribution was managed by Prof Chantal Van Audenhove and Mr Luc Zelderloo.

Catholic University of Leuven, LUCAS

In 1988 LUCAS was established as a collaboration between the Catholic University of Leuven (K.U.Leuven) and Caritas Catholica Vlaanderen. The tasks of this interfaculty centre include research, education and provision of services in the field of health care, welfare and international solidarity. LUCAS' research is mainly applied, practically-oriented, and policy-supporting research. It deals with various target groups: mentally ill people, elderly people with dementia, disabled people, young people, etc. Furthermore, LUCAS treats a diversity of research topics such as professional and informal care, quality of care, discrepancies between needed and provided care, relations between caretakers and care-receivers, expressed emotion, community support systems, stepped-care programs, case management, violence, mobbing, discrimination, etc. Despite the diversity there is a specialization in a few lines of research.

Prof Chantal Van Audenhove is the Head of the Centre for Research and Consultancy in Care in LUCAS. Her research interests vary from the care of older people including those with dementia, research on mental health, including work on transition to community services for people with mental health problems to more general work on care and caring. She has also been involved in cross-national research on mental illness.

EASPD

The European Association of Service Providers for Persons with Disabilities (EASPD) promotes the equalisation of opportunities for people with disabilities through effective and high quality service systems in Europe. EASPD represents more than 7000 service provider organisations in 24 European countries. EASPD has been involved in several European & EU projects in the last four years (including projects on *Combating against Discrimination towards community based settings for persons with disabilities* and *Included in Society*) and has an extensive network active across Europe. Mr Luc Zelderloo is Director of EASPD.

Other people involved from these two groups have been Hilde de Keyser, Anja Declercq and Melanie Demaerschalk.

Reference group

In addition to the research partners, there has been a reference group consisting of representatives from the European Disability Forum, Inclusion Europe, the Mental Health Initiative, Open Society Institute and the European Commission.

Representatives from each of these stakeholder organisations attended project meetings held at key points during the project to assist with the interpretation of the data collected and the synthesis required for the final report.

Inclusion Europe

Inclusion Europe is the European Association of Societies of Persons with Intellectual Disability and their Families. Inclusion Europe is a non-profit organisation which campaigns for the rights and interests of people with intellectual disabilities and their families throughout Europe. Inclusion Europe co-ordinated the *Included in Society* project which is the precursor to the current tender and has worked closely with most of the members of the consortium in the past on a variety of different projects.

European Disability Forum

EDF is a European organisation representing more than 50 million disabled people in Europe. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens' full access to fundamental and human rights through their active involvement in policy development and implementation in the European Union. EDF member organisations reflect a broad geographical base and a wide range of concerns across the disability movement. The membership includes 17 national councils of disabled people from all EU and EEA Member States. In addition, there are 67 organisations on European level, 23 organisations on national, regional and local level and 32 individual members.

Mental Health Initiative, Open Society Institute

The Mental Health Initiative, a part of OSI’s Public Health Programs, aims to ensure that people with mental disabilities (mental health problems and/or intellectual disabilities) are able to live as equal citizens in the community and to participate in society with full respect for their human rights.

Mental Health Europe

Mental Health Europe is a non governmental organisation which aims to promote positive mental health, prevent mental distress, improve care and provide advocacy for people with mental health problems. MHE also works to ensure the protection of human rights of users of mental health services, patients of psychiatric hospitals, their families, and their carers.

Autism Europe

Autism-Europe is an international association which aims to protect and advance the rights of people with autism and their families and work with people to improve their quality of life. Autism-Europe works across 31 European countries and brings together parent associations, governments and other European and international institutions. It has played a particular important role in raising public awareness about autism and other disabilities and in particular those with complex needs. It has good links within the World Health Organisation and represents its members in the European Commission, The Council of Europe and the European Parliament.

Appendix 2
Illustration of availability of data and the process required to obtain data for the template

Appendix 2: Illustration of availability of data and the process required to obtain data for the template

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
Austria	No national data in existence	All published reports on national and federal level	All government officials were contacted by written letters, e-mail and phone.	A planned visit was cancelled. The national ministry responded in a letter that an interview visit to Vienna will not be helpful because there are no national data. Most governments on regional/federal level said they did not have the requested data and did not have the resources to produce them. When a reduced template was sent the answer was the same. So	No template possible – data only available regionally
Belgium	Yes for all except Brussels	2: Services etudes, statistiques et methods (AWIPH) and Vlaams Agentschap voor Personen met een handicap	Yes (mostly successful) – 6 agencies/people provided info. Direct link with AWIPH for Wallonian data	Yes with 3 local representatives from Vlaams Fond and Vlaams Agentschap.	
Bulgaria	Yes by National Statistical Institute and Ministry of Health (National Centre for Health Information)	6: mainly Ministry of Health, National Statistics Institution, Agency for social assistance and Ministry of Labor and Social Policy.	Yes, 2 successful	Yes (interviews with rep from Ministry of Health and Agency for Social Assistance)	Requests to obtain further data not fulfilled
Cyprus	Very limited data (for adults) and only mental health partial data for children via Annual Reports from the Ministry of Labour and Social Insurance, Department of Social Welfare Services, Ministry	5: Health Survey (2003). Statistical Service. Ministry of Health; Annual Report (2005). Department of Social Welfare Services; Annual Report (2003). Ministry of Labour and Social Insurance; Statistical	No. All contacts attempts were unsuccessful.	No (no responses to request for information)	Template completed but many data about places, staff and number of places per type of disability missing.

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
	of Health.	Service of the Republic of Cyprus http://www.pio.gov.cy/; Health and hospital Statistics (2005). Statistical Service. Ministry of Health.			
Czech Republic	Yes through the Czech Statistical Office and the Institute of Health Information and Statistics	5: mainly Czech Statistical Office and the Institute of Health Information and Statistics but also Institute on Information in Education and the Leonardo da Vinci Project.	Yes, successfully	Interviews on definitions with rep. from Ministry of Health, Ministry of Labour and Social Affairs, Prison Service of CR, Ministry of Education (tel. contact). Competences of data – interview with rep. from Research Institute of Labour and Social Affair, Institute on Information in Education, Institute on Health Information and Statistics), two other interviews with experts from NGOs helpful	Templete completed but not many data available (they are not gathered at the moment, but this will change during 2007 – data from new system of registration of social services should be available)
Denmark	Information on ID, PSD is collated (aggregated) at national level from register data collected at municipal level annually to provide limited macro statistics which are accessible electronically on registration (more detailed information in Danish only).	3: Statistics Denmark (main source). National Board of Health/ Statistical Yearbook 2005 OECD Health Data 2005 (www.irdes.fr/ecosante/OCDE/506.html)	Min Social Affairs – successful. Statistics Denmark moderately helpful. No response from: National Association Local Governments (for municipal data), Ministry of Health, Danish Disability Council, National Information and Research Centre for Persons with Disabilities, Danish Council of Organisations of Disabled People	On-site visit and meetings with sources, 18-20 March 2007. Ministry of Social Affairs, Centre for Social Service, Social Research Institute	Template partially complete where data exists at national level. Good data exists at municipal level No information on elderly care at national level, no staffing information

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
			Additional phone calls/email contacts Soren Andressen.		
Estonia	Yes by Ministry of Social Affairs, Ministry and also Ministry of Education and Science	3: mainly the statistical reports from institutions collated by Ministry of Social Affairs.	Yes	Yes, on site interviews with 2 people from Health Statistics Dept of Ministry of Social Affairs,1 from Dept of Social Policy Information and Analysis and 2 from Ministry of Education and Science	
Finland	Data on disability collected at municipal level (from registers) and collated for national info by STAKES. Macro level only. Limited access to statistical tables electronically.	5: SOTKAnet (www.sotkanet.fi) Register of Municipal Employees (Statistics Finland) (www.stat.fi) Care & Services for Older People, 2002 (STAKES) Stakes in Focus, 2005 Statistical yearbook on social welfare and health care, 2005 (STAKES)	STAKES main source. No response from; Min Soc affaires and Health, Association of Finnish Local and Regional Authorities. All other contacts referred me to STAKES. Additional phone calls and email contact with STAKES	On-site visit and meeting with sources 28-31 August 2006. STAKES, Finnish Association Mental Retardation .	Template completed – some data categories missing. No information on staffing, mental health care (other than admission/discharges). Problems with national data on children with disabilities because only 50% municipalities collect data.
France	Yes – mainly through CTNERHI in Handicap en Chiffre, 2005	2 Handicap en Chiffre and Etat des lieus des pratiques en CAT	No	UNAPEI confirmed accuracy and completeness	Template completed by UNAPEI
Germany	Yes – through Statistisches Bundesamt: Sozialhilfestatistik und Pflegestatistik (2005) BAG der Freien Wohlfahrtspflege (Gesamtstatistik) 2004, Berlin, Bundesministerium		Yes	Yes, the commentary was communicated with the ministry official (M f. Social Affairs)	

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
	für Familie, Senioren, Frauen und Jugend (BMFSFJ 2006) Con_sens (2005): Kennzahlenvergleich der überörtlichen Träger der Sozialhilfe 2005. Pflege im Rahmen der Pflegeversicherung – Deutschlandergebnisse, Wiesbaden, ZPE der Universität Siegen: (2005): Zwischenbericht zur wissenschaftlichen Begleitforschung (IH-NRW)				
Greece	No	Disability Now. www.disabled.gr ; European Coalition for Community Living. Newsletter, Issue No. 4, July 2007. http://www.community-living.info; Constantinopoulus A, Mental Health Economics Questionnaire - The case of Greece. MHEEN-I Country Reports. MHEEN, 2005; Data provided by the Ministry of Health and Solidarity.	Yes, after many attempts the Ministry of Health and Social Solidarity was contacted: Ms Mavratzotou Kalliopi. Director of Protection of Persons with Disabilities at the Ministry of Health and Social Solidarity and Mr. Georgakopoulos G. Initial contacts with Mr Sotiris Georgopoulos were unsuccessful and contact was received from his replacement, Ms. Kalliopi too late to be included in the	No	No template completed as no enough reliable data.

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
			project report.		
Hungary	Yes: - aggregate data on number of services, places, type of providers, service users (by gender and age groups) collected by the Central Statistical Office on a yearly basis. No data on service users by type of disability.	3: Szociális Statisztikai Évkönyv 2004 (Yearbook on Social Statistics 2004); 2001 Census report and tables; TEIR szociális ágazati adatbázis (on-line database with institutional level data)	Yes – Ministry of Social Affairs and Labour	Yes – interviews in Aug 2006 with Zsuzsa Csató Disability Consultant, National Institute of Social and Family Policy (NCSSZI); Renáta Szrena, Dept. of Disability Affairs and Rehabilitation; Ákos Erdélyi, Dept. Of Family and Social Services, all under Ministry of Social Affairs and Labour	Template completed
Ireland	Yes for ID and PD/SD in form of register of people (not at level of services). Some limited statistics available from Central Statistics Office electronically.	6: NIDD database; NPSDD database; HRB (2006) Activities of Irish Psychiatric Units and Hospitals Census Bulletin (Health Research Board, Ireland); HSE (2006) Provision of Disability Services by Private Organisations; Directory of Service Providers for Children with Disabilities (HRB 2001); Central Statistics Ireland (www.cso.ie)	Yes HRB (responsible for national databases) good contact. No response from other key organisations inc: Health Services Executive, Dept Health & Children, Special Residential Services Board. Additional phone calls Caraoisa Kelly, draft templates provided by HRB.	On-site visit and meetings with sources 26-30 September 2006: National Intellectual Disability Database, National Physical & Sensory Disability database, Health Research Board.	Template completed – some data categories missing Information on mental disability in form of in-patient registers which do no record length of stay by client. Gaps in information on national level for elderly in church-based residential accommodation.
Italy	Yes, by ISTAT –Italian Statistics Institute- and by the Ministry of Health.	5: Disabilitá in cifre.. http://www.disabilitaincifre.it/ ; Italian Statistical Institute. Statistical. http://www.istat.it/ ; Ministry of Social Solidarity. Disability Area.	Yes. initial contact with the Director of the V Division in the Ministry of Social Solidarity for the Policy for People with disability. Some difficulties following political changes with	Yes. Three visits took place. 2 interviews with the Istat members were conducted and an interview with Mr. Gi Giuseppe Tibaldi. MHEEN Network. EPCAT GROUP.	Template completed. Few data missing.

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
		http://www.solidarietasociale.gov.it/ ; http://www.disabili.com/ ; Amaddeo F, et al 2007; Ministry of Health. http://www.ministerosalute.it/	election. Contact established with the new general director for social inclusion and social rights and for Corporate Social Responsibility (CSR): but near the project deadline for data collection. Main contact has been the Italian Statistical Institute. Ms. Alessandra Batisti and Ms. Roberta Crialessi at the Health and Welfare Service department.		
Latvia	Yes, by different agencies – eg. Minstry of Education, Minstry of Health etc.	3 MHState Agency information system, Statistic Yearbook on Mental Health Care, and WHO_AIMS report on MH systems in Latvia	Yes - from Department of Social Services and Social Welfare, Ministry of Health	Yes – onsite interviews with 2 people from Dept of Social Services and Social Welfare, 3 people from Ministry of Health, and 2 from ministry of Education and Science.	
Lithuania	Yes – by Department of Statistics	6: Reports from Department of Statistics on Social Integration and on Social Services and from Health Information Centre and the Ministry of Health Care. Plus official letters to Ministry of Social Security and Labour	Yes and template completed in cooperation with Ministry of Social Security and Labour	Template completed locally	Template completed with official from the Department of Affairds of the Disabled under the Ministry of Social Security and Labour.
Luxembourg	Yes - annual report of the Ministry of Family and Integration	1 – annual report of the Ministry of Family and Integration	Yes, Ministry of Family and Integration	No	Template completed by official from Ministry of Family and Integration
Malta	No national data collated – some very limited more	5: Ministry of Health, the Elderly and Community	Main contact through National Commission for	On-site visit to Malta and meetings with sources 10-13	Template completed. Staffing data missing.

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
	general information from National Statistics Office available electronically.	St Vincente de Paule Residence KNPD Mount Carmel Hospital Agenzija Sapport	Persons with a Disability (KNPD) and Agencija Sapport. No response from Ministry of Health, Elderly and Community, Appogg, Department of Health Information, NGOs, University of Malta. Additional telephone calls, emails and faxes sent to service providers, NGOs requesting assistance – no response.	April 2007: National Council for Persons with a Disability (KNPD), St Vincente de Paule Residence, Agenzija Sapport, Mount Carmel Hospital.	
Netherlands	Yes – web-based	3: www.brancherapporten.minvws.nl, Statistiek personelssterkte 2004: gehandicaptenzorg and Van der windt and Talma (2006)	4 officials/local people contacted	Yes (Mineke Hardeman)	
Poland	Yes, data available for purchase from Polish Central Statistical Office (CSO)	2: Polish Statistical Office (CSO); Dept. of Social Assistance and Integration, Ministry of Labour and Social Policy	Yes, Dept. of Social Assistance and Integration, Ministry of Labour and Social Policy; Ewa Wapiennik, Academy of Special Education	Yes	Template completed
Portugal	Only for Mental Health services run by the Ministry of Health. Many services are run by religious organisations and there is not data at a national level nor a catalogue of services.	6: Ministry for Labour and social Solidarity http://www.mtss.gov.pt/ ; Ministry of Health http://www.dgs.pt/ ; Government of Portugal http://www.portugal.gov.pt/ ; SNRIPD -Secretariado	Yes. The SNRIPD – National Secretary for the Rehabilitation and Integration of People with disability- was contacted. The University Nova of Lisbon was also contacted.	Yes. Dra. Luísa Portugal SNRIPD María Isabel Fazenda SNRIPD Prof. Miguel Xavier. Universidad Nova de Lisboa. Prof. Mónica Oliveira. Instituto Superior Técnico.	Template completed but many data missing. There is not too much disaggregated information overall for residential social services.

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
		Nacional para a Reabilitação e Integração das Pessoas com Deficiência http://www.snripd.pt/ ; Mental Health Economics European Network. MHEEN. http://www.mheen.org/ ; Irmãs Hospitaleiras do Sagrado Coração de Jesus. http://www.ihscj.pt/		Departamento de Engenharia e Gestão.	
Romania	Yes, but not easily available – limited data on the web. Excellent data from ANPH for adults: little data from ANPCA on children	4. National Authority for People with Handicaps (ANPH); National Authority for Protection of Children (ANPCA); Specialised Public Services for Social Assistance and Child Protection, January 31, 2005 (www.anpca.ro); Important Highlights Related to Mental Health Policies and Legislation in Romania (www.ms.ro)	Yes, 3 successful	Yes, interviews with reps from ANPH, ANPCA, and The National Institute for Prevention and Combating Social Exclusion of People with Disabilities	Data on children incomplete
Slovakia	Not in format required	10: reports from each of 8 regions and from Ministry of Education and Ministry of Health	Yes	Yes – 3 people within Dept of Integration of persons with disabilities and Social Services, 2 from Ministry of Health and 1 person from the Ministry of Education and Science	
Slovenia	Only for children and school placements, not on intellectual disabilities	1: Open Society Institute: Rights of People with intellectual Disabilities	Yes - intensive efforts made to gain data from ministry of Labour, family and Social		Only very small parts of template could be completed

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
			Affairs, National Institute for Education and the Ministry of Health but without success		
Spain	Yes. There is aggregated information for mental health published yearly by the Ministry of Health. Also the Ministry of Work and Social Issues promotes the DESDE Project, a service catalogue that collates information from all the Autonomous Regions. Database from the Ministry of Health does not provides information about resident´s gender, age, etc.	7: La Discapacidad en Cifras. IMSERSO, 2002 (PDF); Las Discapacidades en España: Datos estadísticos. (2003) Real Patronato sobre Discapacidad. (PDF) ; Encuesta sobre discapacidades, deficiencias y estados de salud. (1999). Datos básicos Instituto Nacional de Estadística ; DESDE Project. www.proyectodesde.com Information about services in different Autonomous Regions; Catálogo Estatal de Servicios de Discapacidad. Proyecto DESDE ; Catálogo Nacional de Hospitales 2007. Ministerio de Salud y Consumo; Estadística de Establecimientos Sanitarios con Régimen de Internado. Información Anual. Año 2005.	Yes. Mr J. Salazar and Mr. J. Salgado from the Agency for Ageing and Dependency at the Ministry of Work and Social Issues were contacted. Different officers at the Social Services departments and at the Health departments on the 17 Autonomous Communities in Spain also collaborated in the data collection when possible. Responsibles for the DESDE project participated in the data collection and the report writing.	Yes. Mr J. Salazar and Mr. J. Salgado from the Imserso. Miriam Poole as responsible for the DESDE Project. Officers from the Social Services Departments i.e. Murcia, Madrid and Cataluña.	Template completed. Accurate data for number of places and number of places per type of disability. Few data on residents characteristics as gender and age. Also few data for staff numbers and training. Some sections have been reported only for partial data from different Autonomous Regions. Regionalisation is a major problem in Spain for data collection.
Sweden	No national statistics except where municipal or local authority register database information is collated	3: National Board of Health & Welfare (2006) “Funktionshindrade personer – insatser enligt	National Board for Health and Welfare and Statistiks Sweden provided most assistance. Some support	Meetings 05/12/06, 06/12/06, 07/12/06 Socialstyrelsen Ministry for Health &	Template completed. Some data missing – little information on elderly. Poor data on people with mental

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
	(PSD, ID), providing global data on numbers but not by service level. Data available electronically on registration.	LSS år 2005; National Board of Health & Welfare (2006) Funktionshindrade personer år 2005.; Statistics Sweden:Local authority accounts Annual Report (RS);	from umbrella NGOs. No response from Swedish Association of Local Authorities and Regions, Centre for Disability Research, Handicap and Rehabilitation Research Centre, Disability Ombudsman, Swedish Insitute of Social Research, Swedish Disability Fedreration. Additional phone calls/emails to Socialstyrelsen.	Social Affairs,	health problems as data held at Regional level only.
Turkey	No. Data provided on request. We had access to the raw data within the Social Services and Child Protection Agency – SHÇEK-. Data on mental health services were provided also in request.	The main information source for template compilation have been the data provided by the Social Services and Child Protection Agency – SHÇEK- and the Ministry of Health.	Yes. The Social Services and Child Protection Agency, the Administration for Disabled People and the Ministry of Health were contacted and collaborated actively in the report writing.	Mr. Tolga Duygan. Administration for Disabled People. Ms. Irem Cosansu Yalazan. Social Services and Child Protection Agency and Ms. Sonnur Ünal. Social Services and Child Protection Agency were interviewed.	Template completed. This is one of the most complete templates althought some data overall for mental health services are missing
UK	In England – some global statistics on how many people funded by LA. Also had access to Social care data at individual service level. In Scotland – there are collated statistics on places, homes, types of providers and service users by type of	24: Care Commission (2005) Annual Report and Financial Statement Scotland Social Work Services (2005); Care Commission (2004) A Review of the Quality of Care Homes Scottish Executive: Social Focus on Disability, 2004;	Scottish Care Commission contacted for raw data but without any success. Phone calls with representatives from Department of Health Social Services and Public Safety, Registration and Inspection Unit to confirm that most recent data had been	No	4 templates had to be completed as situation different in each of England, Scotland and NI

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
	disability. Relevant data collected at the level of services (by the Scottish Care Commission), reports are open access but very limited statistics produced. There is hardly anything on staff. Data collection seems somewhat random – no yearly data.	Scottish Executive Scotland: Community Care Statistics 2001; Scottish Executive: "Home at Last" (2003); Scottish Executive: Scottish Care Homes Census (2005); Welsh Assembly Government (2006) Key Health Statistics for Wales; NAW Statistical Directorate (2006) Staffing of Local Authority Social Services; Welsh Health Survey (2003); National Assembly for Wales (NAW) (2006) Hospitals & Units for People with Mental Illness (Stats Bulletin); National Assembly for Wales (NAW) Health and Social Services Committee - Report on Interface Between Health & Social Care (2005); Care Standards Inspectorate for Wales (CSIW) Annual Report 2005-2006; Department of Health Social Services and Public Safety, Registration and Inspection Unit (NI) 2003-2004; NI Statistics & Research Agency (NIRAS); Department of Health SSPS Community Statistics 2003-2004 Hospital Statistics	obtained.		

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
		2003/04; NHS Health & Social Care Information Centre: Residential & Nursing Care Placements (2006); Local Authority workforce Intelligence Group, Social Care Workforce Study, 2006, No. 36. Adult, Children and Young People Local Authority Social Care 2006; DoH National Statistics - Statistics Bulletin Community Care (2004); Department of Health (2006) Hospital Activity Statistics - Residential Care Beds http://www.performance.doh.gov.uk/hospitalactivity/data_requests/residential_care_beds.htm; Commission for Social Care Inspection (2007) *The state of social care in England* 2005-2006 http://www.csci.gov.uk/default.aspx?page=1852&key= ; Annual Reviews in Independent and Non-Maintained Special Schools http://www.scrip.uk.net/ ; Department for Education and Skills/Department of Health. (2004). *Disabled Children in Residential Placements*. London:			

Country	Existence of available collated statistics at national level	Number of sources used to complete templates	Were government officials/local experts contacted (successful?)	Visits to clarify definitions and completeness	Other comments
		Department for Education and Skills/Department of Health; Pinney, A. (2005). *Disabled children in residential placements*. London: Department for Education and Skills; Home Office Statistical Bulletin 05/07 Mentally Disordered Offenders 2005			

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