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

Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 1: executive summary

Discussion paper [or working paper, etc.]

Original citation:

This version available at: http://eprints.lse.ac.uk/3459/

Originally available from The Tizard Centre, University of Kent

Available in LSE Research Online: Jan 2012

© 2007 University of Kent

LSE has developed LSE Research Online so that users may access research output of the School. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LSE Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain. You may freely distribute the URL (http://eprints.lse.ac.uk) of the LSE Research Online website.
Acknowledgements
The authors would like to acknowledge the contribution of the following to this report:

PSICOST, Spain: Prof L Salvador-Carulla, Rafael Martinez-Leal, M Poole, J A Salinas and A Romero
University of Siegen, Germany: Dr J Schädler, Dr A Rohrman and A Frindt
Charles University, Prague: Prof J Siska, B Vann, J Vránová
Leuven University, Belgium: Prof C van Audenhove, M Demaerschalk, A Declercq
University of Kent, UK: R Hayward, A Kozma
European Association of Service Providers for Persons with Disabilities, Brussels: L Zelderloo, H de Keyser
Inclusion Europe, Brussels: I Kömer, G Freyhoff
Mental Health Europe, Brussels: J Henderson
Autism Europe, Brussels: D Vivanti
European Disability Forum, Brussels: C Besozzi
Open Society Institute Mental Health Initiative, Budapest: C Parker

Part of the costs of printing this report were met by contributions from the Tizard Centre and the Zentrum für Planung und Evaluation Sozialer Dienst.

ISBN
978-1-902671-49-9

Citation

Disclaimer
The views expressed in this report are those of the authors and do not necessarily reflect those of the European Commission.

Cost
The cost of this project was €349781.
Contents

1. INTRODUCTION ................................................................. 1

2. METHOD ............................................................................. 3

3. CONCLUSIONS AND RECOMMENDATIONS .................. 4

   REVIEW OF EXISTING SOURCES OF INFORMATION ................. 4
   Recommendations ................................................................. 4
   1. Agree a harmonised data set at European level ...................... 4
   2. Publish statistics demonstrating progress in each country .......... 5

   THE CHANGE PROCESS IN THREE COUNTRIES .................. 5

   COST-EFFECTIVENESS OF COMMUNITY VERSUS INSTITUTIONAL MODELS OF RESIDENTIAL CARE AND
   CHANGE OVER TIME ............................................................ 6
   System structures .................................................................. 6
   Policies and plans .................................................................. 6
   Costs, needs and outcomes ..................................................... 7
   Supply constraints .................................................................. 9
   Local economic development ................................................ 9
   Opportunity costs of capital ................................................. 9
   Funding flows ...................................................................... 10
   Multiple funding sources ..................................................... 10
   Dynamics of change ............................................................ 10

   RECOMMENDATIONS .......................................................... 10
   Strengthening the vision of new possibilities in the community .... 11
   3. Adopt policies in favour of inclusion ........................................ 11
   4. Develop legislative support for inclusion ............................... 11
   5. Strengthen the voice of disabled people, families and their advocates in policy .......................... 12
   6. Require professional bodies to make their policies consistent with supporting inclusion .............. 12
   7. Encourage media interest in and support of inclusion .............. 12
   8. Learn from best practice in other countries ............................ 12

   Sustaining public dissatisfaction with current institutional arrangements ............................................. 12
   9. Open institutions to independent scrutiny ............................. 12
   10. Create inspectorates to protect and promote the rights of individuals .............................................. 13
   11. Emphasise comparisons of quality of life ............................... 13

   Creating some practical demonstrations of how things can be better ..................................................... 13
   12. Create innovative services ................................................ 13
   13. Include everyone from the start ............................................ 13

   Reducing resistance to change by managing incentives for different actors in the process ..................... 13
   14. Create new funding opportunities ........................................ 13
   15. Remove obstacles to development of services in the community ................................................... 14
   16. Make funding of new services contingent on quality ................................................................. 14
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 most wide-ranging study of its kind ever undertaken.

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. This 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.

- **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.

- **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. This means supporting people’s decision-making to achieve the best balance between their wishes and society’s responsibility for their care.

This approach is sometimes referred to as ‘supported living’ or ‘independent living’. These services support people to live as full citizens rather than expecting people to fit into standardised models and structures.

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. Evidence from research and evaluation of alternatives to institutional care also supports the transition to services in the community. Where institutions have been replaced by community-based services, the results have generally been favourable. 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. Developing appropriate services in the community is a necessary, but not a sufficient, condition for better results.
The overall aim of this 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 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.
3. Report on the issues identified, addressing the results of the project, the adequacy of the data available in each country, and making recommendations for the cost-effective transition from institutions to community-based services.
2. Method

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. Informants were asked to supply information about all residential care establishments serving disabled people in each country, to permit examination of the current balance between institutional and community care. The study covered all age groups and all kinds of disability, including mental health problems.

The study involved a number of elements:

- Existing European and international data sources were reviewed to identify material relevant to the study. These included official reports, reports from non-governmental organisations as well as specific studies.
- Existing national data sources were identified and collated, using published material augmented by telephone and email contact and visits.
- Definitions, completeness and quality of the data was checked.
- The data were analysed and prepared for presentation.
- The sequence and process of service development was described in three countries selected as case studies – England, Germany and Italy.
- As part of this review, particular attention was paid to the roles of different actors (national, regional and local tiers of government), the role of disabled people, their families and representatives and the role of staff and their organisations.
- Evidence about the economic implications of shifting from institutions to services in the community was collated from available research in England, Germany and Italy. Attention was paid to ensure ‘like for like’ comparison, taking account of the level of disability of residents, the range and level of quality of services achieved and the balance between costs met by public agencies and those met by others, especially the families of disabled people.
- The available evidence was examined to understand the extent to which transitional cost (eg ‘double-running’ expenditure) issues were important.
- 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.
- The interim report, final report and executive summary were prepared by the 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 report with project partners and with the European Commission.
3. Conclusions and Recommendations

The main report of the study is presented in Volume 2, with the detailed reports for individual countries in Volume 3. The following section of the report summarises the conclusions of the study, starting with the conclusions and recommendations drawn from the review of existing information. It will then present the conclusions drawn from the analysis of the process, costs and outcomes of developing effective services in the community to replace institutions and the 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 1. 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).

![Figure 1 Effect on costs and quality of transfer to good services in the community](image)

<table>
<thead>
<tr>
<th></th>
<th>Costs</th>
<th>Quality</th>
<th>Cost-effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Less expensive institution</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less disabled person</td>
<td>Lower</td>
<td>Same or higher</td>
<td>Same or better</td>
</tr>
<tr>
<td>More disabled person</td>
<td>Higher</td>
<td>Higher</td>
<td>Same or better</td>
</tr>
<tr>
<td><strong>More expensive institution</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less disabled person</td>
<td>Lower</td>
<td>Same or higher</td>
<td>Better</td>
</tr>
<tr>
<td>More disabled person</td>
<td>Same or lower</td>
<td>Higher</td>
<td>Better</td>
</tr>
</tbody>
</table>

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 (e.g. 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.
With the support of the European Union