Kaarlo Laine
Kirsti Kuusterä

DE-INSTITUTIONALISATION IN EUROPE

Literature Review and Meta-analysis on de-institutionalisation

KEHITYSVAMMALIITON SELVITYKSIÄ
REPORTS OF FINNISH ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 2/2008

CONTENTS

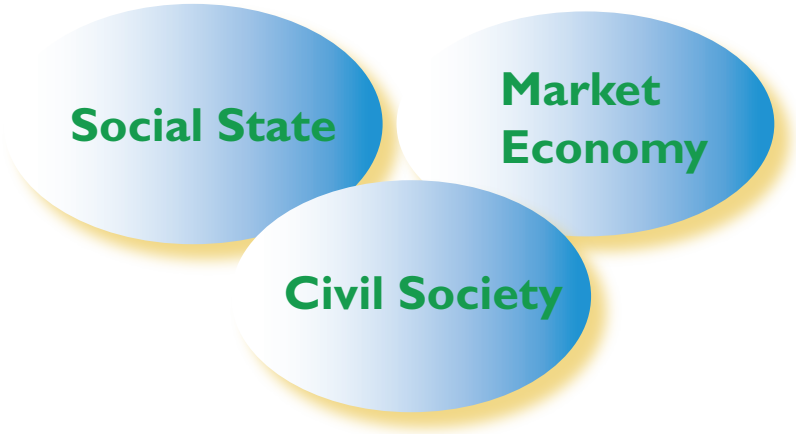
Introduction, basic conceptualizations and the aim of the study

European Association of Service Providers for Persons with Disabilities (EASPD) and its members have, on behalf of the Finnish Association on Intellectual and Developmental Disabilities (FAIDD), gathered research materials dealing with de-institutionalisation. FAIDD has launched a study on the subject. The goal of the research is an overview of the literature on the topic and a meta-analysis of de-institutionalisation as a societal process in Europe.

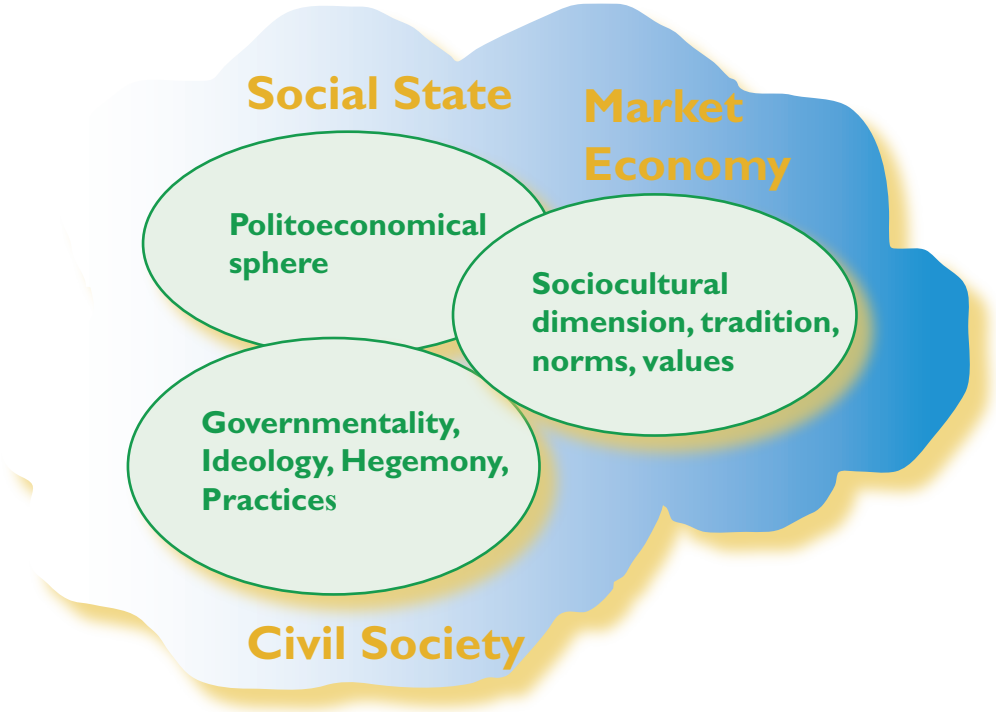
De-institutionalisation as a societal process can be traced back to the 1960s. Historically, this emerged most forcefully in Europe, notably in Italy. The Italian government even stopped admissions to large institutions in 1980 after a long and at times even bitter struggle for and against the cause. Ever since, the pace and content of the process has varied dramatically throughout Europe. However, in general de-institutionalisation refers to a process where large numbers of people are transferred from large institutions to the community or into smaller units. These smaller units include care in community, foster or family homes, group homes, "open institutions" etc. There is no single given or fixed meaning attached to the process, rather there is a myriad of things that can be seen as part of the phenomenon. Before taking a closer look at the data, we start with a short guide to how to understand de-institutionalisation on different levels in the context of society.

De-institutionalisation is part of the institutional order of society. It is always tied to larger social change, and as such it tells us stories about the individual and the community, and further about the values and norms of the community. At present, societies are part of a global system of world economy, of integration in Europe, the EU. Welfare society is an institution consisting of many institutions, and de-institutionalisation is a mode or phase, stage of a change in that system. It is also a question of politics and power, and of decisions and of course resources and their allocation in a given society. For instance keywords like normalisation, integration and inclusion, often used today, reflect these ideas and actions, as do the notions of community care or individual care. Discussions related to de-institutionalisation bring to the surface notions of people, individuals, and types of deficiency, and moreover the concept of structure, as well as type of care (in community) for certain kind of people classified to different categories (Kuusterä & Teittinen 2008).

Back in the 1960s, de-institutionalisation constituted a social movement in itself. It was a question of human rights, of human dignity, justice, and equality. It led to gatherings, protests and organized associations along with political parties for people in institutions. This was a social movement for civil rights, in Civil Society. Today we are witnessing a change in the relationship between Social or Welfare State and Civil Society. There is a long-lasting discussion about the limits of the Welfare State, about "giving it back" to families, to community. In Finland, Raija Julkunen, a well known social scientist, has proclaimed that there is a debate going on over who is responsible for caregiving in times where the welfare state has downsized budgets and human resources. This has been called the hour for the third sector to take charge. Along with this we can see "welfare mixed", which means commodification of care. De-institutionalisation is increasingly shaped from the direction of market economy. Following Esping-Andersen (etc. 1990), modern society consists of three spheres: Social State, Market Economy and Civil Society. These are also spheres or poles of vital importance with regard to de-institutionalisation. How are these spheres connected with each other, how do they frame the issue, and further, how are they structured in different countries? In addition, what are the historical lineages of these subjects and how are they organized?



Against this societal background, one can differentiate between the Sociocultural dimension, Governmentality, Ideology, and Practices, as well as the Political and economical factors of de-institutionalisation.



Sociocultural dimension refers to traditions, norms and values of communities and societies (see e.g. Goffman 1970). They are inherent in ways people interact and in the kind of meanings that are transferred. Further still, these are bottom lines with regard to how care and custody are reconstructured and how the "culture of de-institutionalisation" (and institutionalisation) is taking place (Castoriadis 1998) (e.g. Italy, Post-socialist/-communist countries).

Governmentality is about dominance and power (see e.g. Rose 1999, Foucault 1991, Elias 2000, de Swaan 1990). Institutionalisation/de-institutionalisation is also always an ideological question. In addition, hegemony is materialized in practices and ways of organizing care. Of crucial importance is the position of patients, the handicapped, or children in the "system of de-institutionalisation".

The politoeconomical factor is about interests and resources, about which and whose needs are met and how. Which interest groups are getting their message through and how is the allocation of resources taking place? Who carries the responsibility for care, and the "weight" of de-institutionalisation? Is it the individual, family, community, or public or private organization? This can be seen as a "regime of de-institutionalisation" (e.g. Julkunen 2006, Kosonen 1995, Esping-Andersen 1990).

The ideology behind social security systems and welfare state orientation

In the following chapters the idea is to look at the ideologies behind the chosen social systems and welfare state orientations. Exploring these ideologies of welfare state is helpful also when examining the de-institutionalisation development in the sample countries since the welfare state debate covers major ideological issues. This discussion looks at the basis of the chosen systems, and looks at the historical, cultural, economic, political, institutional etc. factors.

In his book published in 1995, Pekka Kosonen (1995, 7) analysed the debates around the welfare state in Western and Eastern Europe. He concluded that in Western Europe the aim was integration, but simultaneously changes in social divisions, economic conditions and in the political field resulted in differentiation of welfare states. In Eastern Europe's transitional economies, the main problem was to find money and political will to construct much needed welfare systems.

All the 13 sample countries (Italy, Greece, Slovakia, Hungary, Bulgaria, Romania, Estonia, Lithuania, Spain, the Netherlands, Germany, Austria and the Czech Republic) can be seen in relation to the discussion revolving around the concept of welfare state and the different welfare regimes.

Social security programs

According to 'Social Security Programs throughout the World' report (2006, table 1), all the sample countries had extensive social security programs. Programs covered old age, disability and survivors, sickness and maternity (cash benefits for both, cash benefits plus medical care), work injury, unemployment, family allowances. The only exception is the Netherlands where work injury coverage is provided under other programs or through social assistance.

	Total population (millions)	GDP per capita (euros)
Austria	8.1	25,279
Bulgaria	7.7	6,494
Czech Republic	10.2	13,740
Estonia	1.3	11,373
Germany	82.6	23,315
Greece	11.1	16,761
Hungary	10	12,251
Italy	58	22,780
Lithuania	3.4	9,830
Netherlands	16.2	24,672
Slovak Republic	5.4	11,335
Spain	43	18,808

Source: Social Security Programs throughout the World (2006, table 3).

Welfare regimes

The grouping of welfare states according to type has a long tradition. Richard Titmuss made the classical distinction between residual and institutional welfare states in the 1950s and it has been used since to describe the historical development and to testify the differences between welfare models (Kosonen 1995, 20–21). In the residual model, individuals themselves carry the main responsibility, and the state steps in only when the family or the market fails. In the institutional model the state offers services to the entire population. (Look at Esping-Andersen 1990, 20; Kosonen 1995, 20–21.)

Corden and Duffy (1998, 105) pay attention to the solidarity behind different welfare models. The Bismarckian tradition flourishing in Continental Europe is based on horizontal solidarity. It is based on insurances and the benefits are thus earnings-related. The Beveridgian tradition, named after the British economist and social reformer, is tax-financed and generalised. The solidarity thus covers all the citizens but the benefits tend to be lower and less relative to the average income.

Another, partly overlapping, distinction can be made between the employment based and residence based models. Germany applies the employment based model where social benefits are financed with social insurances that cover the employee and his/her family members. In residence based models, the social benefits are channelled to individuals. The Nordic countries, the Netherlands, and Great Britain apply this model. The juridical base of social security varies as well from country to country. In parts of Europe, contracts between labour market organisations are central. The option is statutory social security. (Saari 2003b, 181–182.)

Risto Eräsaari (1995, 184) divides traditional welfare models into social right model, residual model and redistribution model.

Family values and the role of family are an important factor that varies from one welfare regime to other. In some countries, family is an essential welfare provider, especially with children, the elderly, and disabled persons. Birgit Pfau-Effinger and Birgit Geissler (2005, 34–37) have discussed welfare values, care and different welfare regimes. Welfare values can be tracked down from the attitudes towards the care providing institutions. The second important question is the nature of social rights in relation to care: should they be family-based or individual. Thirdly, Pfau-Effinger and Geissler mention the re-distributive role of the welfare state and the quality of social rights. When European countries are classified based on the welfare values, the result is rather concurrent with the Esping-Andersen model of three welfare regimes.

The welfare regimes cannot be discussed without referring to the Gøsta Esping-Andersen's seminal work The Three Worlds of Welfare Capitalism (1990). In the study, three countries are used as models of different welfare regime types: Sweden represents the social, Germany the corporatist, and USA the liberal regime. In the comparison, the models' ability to reduce social inequality and class division is central. The liberal model is based on norms of the work ethic and encourages the market. Consequently, the liberal model minimizes the de-commodification effects. In countries like Germany and France, the preservation of status differentation is central and that can be seen in the conservative models. On the other hand, the responsibilities of church and traditional familyhood have shaped the Central European models. The third regime type, the social model, was the result of social democratic reform. The typical trait of this model is the fusion of welfare and work so that full employment is the promise and condition of welfare state. However, Esping-Andersen sees his models as ideal types which do not exist as pure cases.

Pekka Kosonen (1995, 22) sees Esping-Andersen's model as a supplement to the residual/institutional division. The institutional model and the social democratic welfare state are congruent in many ways. On the other hand, he sees the comparison of the liberal welfare state model and the residual model as more problematic.

For example Anneli Anttonen and Jorma Sipilä (1994, 242) have made a more specified classification based on Esping-Andersen's model. They introduce the Nordic public service model, the Anglo-Saxon means-tested model (where benefits are based on a comparison of a person's resources as against a standard measure), the traditional home care model, the German-Dutch subsidiarity model, and the French-Belgian family policy model. This classification is based on the social services' volume, method of production and female workforce participation.

Another Finnish reclassification (Kosonen 1995, 23–25) divides Western-European countries into four categories: Nordic, continental, peripheral, and British. The classification is based on data on employment and social security. In Nordic countries, the level of employment has been high and the aim of social policies has been universalism. The state has provided social services and collected the needed resources from practically all citizens. In continental welfare models, the social expenses have been relatively high. Unlike in the Nordic countries, women take care of children and the elderly and the church and private organisations are important. Kosonen includes e.g. Germany, Austria, Italy and the Netherlands in this group. The rest of South-European countries, e.g. Spain and Greece, belong to the peripheral regime. Between the years 1960 and 1990, the national income and level of social expenditure have been relatively low. In peripheral countries, family and church are central, the state provides limited social security only, and social insurances depend on one's status at the labour market. Economical conditions in these countries have developed vastly during the last two decades, and this has affected their social policies as well. Kosonen sees Great Britain as a peculiar case that does not belong to any of the introduced regimes but cannot be seen as part of the liberal (American or Australian) model either.

Feminist researchers have noted that the studies of welfare regimes have partly ignored the problem of valuing unpaid work which nevertheless greatly structures welfare regimes. Also the importance of the idea of the male breadwinner in different countries is not examined. It is one factor that cuts across the established typologies of welfare regimes. (Lewis 1992.) For example South-European countries such as Greece, Italy and Spain share the especially strong idea of family as a unit of solidarity. According to Elisabet Tejero and Laura Torrabadella (1999, 133–134), however, the states in these countries do not promote the 'breadwinner model' but encourage interdependency between family members.

Maurizio Ferrera (1996) pays attention to the special traits of the welfare model in South-European countries and the factors behind them. He argues that Italy, Spain, Portugal and Greece constitute their own Southern Model of welfare. Ferrera refuses to use only traditional family values or Catholicism as the main explaining factors. In these countries, the income maintenance systems are typically fragmented and corporatist. Clientelism is a persistent phenomenon, and public and non-public actors and institutions work alongside each other in the sphere of welfare. On the other hand, universalistic ideas have been applied to the organisation of health care. Ferrera points out that the state apparatuses have historically been weak in Southern Europe. The political parties have been the main actors of interest articulation (instead of trade unions, for instance) and the ideological sphere has been highly polarized. Thus the 'conservative-corporatist' political scenario common in continental Europe has been much more complicated in these countries.

Ferrera's 'Southern model' has been criticized for ignoring the historical differences in the region (Marinakou 1998, 235–236). Greece, for example, spent a long period under the Ottoman rule while Italy and Spain have been colonial powers. On the other hand, Ferrera does not pay attention to the positioning of the region in world economy. Until the 1960s, Spain and Greece were economically underdeveloped, which should be taken into the consideration when looking at the social ideology and practice in given countries.

Central and Eastern Europe

Just like the South-European countries, Central and Eastern Europe face particular challenges. The welfare regime models have mainly been created to highlight and explain the different welfare models in Western Europe. The former Soviet countries seem to be converging towards Western models but their unique past should be taken into consideration while looking at their present social policies and systems.

Pekka Kosonen (1995, 78–99) argues that welfare systems were developed in parts of Central and Eastern Europe in the 1970s and 1980s, for example in Hungary and Czechoslovakia. The expenditure to social welfare in these countries was in proportion with the Western level, and some of the social policy systems created before the Second World War were developed under the Soviet rule. In practice the social policies were tied to workplaces and the tenet of full employment was followed.

Kosonen (1995, 95) argues that the continuation of welfare systems is based on the benefits and expectations of citizens, and total renunciation of earlier systems is thus difficult. The influence of earlier decisions and existing institutions on the formation of the new systems – or, path-dependency – has been noted in the context of Western Europe as well (see Julkunen 2001, 19; Saari 2003a, 9).

The transfer period has presented two kinds of problems to the welfare systems. Firstly, the new political thought in Hungary and former Czechoslovakia has preferred market ideology to the heritage of socialism. Secondly, belt-tightening and new financial thoughts have affected social security systems. The communist countries had, at least officially, full employment and no insurance systems in case of unemployment. Thus the rising levels of unemployment (10–15 % in Bulgaria, Slovakia, Hungary and the Czech Republic in the early 1990s) gave rise to an economic dilemma. Another severe problem was high inflation (Kosonen 1995, 90–93). The transition has affected pension systems. There have been attempts to avoid increasing expenditures by lowering pensions and increasing retirement age. The problems have prevailed, and as recently as in 2003 Sotiropoulos et. al. remarked that the countries were simultaneously facing demands for greater economical efficiency and the need for enhanced social protection. "Regime change is often linked with high hopes for a better life; otherwise people may tend to downgrade democratic achievements and be less enthusiastic about political democracy itself." (Sotiropoulos et. al. 2003, 657). According to Kosonen (1995, 90–93), the changes made in transitional countries during the early 1990s were mainly mandated by the economic pressure and were answers to an immediate crisis. Kosonen saw the future of welfare policies in transitional countries as hugely dependent on the civil society, which in the mid-1990s seemed passive and frustrated.

Kosonen (1995, 88–89) identifies four phases of transition from socialism to market economy based on Sutela's and Balcerowicz's research. These are the phases of stabilization, liberalization, privatization, and rebuilding. All Central and Eastern European countries have gone through these phases, but the pace of the transition has varied. Two main tendencies are gradual and radical transition. Of the sample countries, Hungary is an example of gradual change with the aim of postponing the social expenses of the transition. The counter-argument to gradual transition is that the existing structures and institutions may easily subdue the attempts to change.

Soon after the transition, Bob Deacon classified the emerging welfare systems into four types. Bulgaria and Romania exemplified post-communist conservative corporatism, Germany conservative corporatism, Czechoslovakia social democracy, and Hungary liberal capitalism regime. (Deacon 1992 page 181, according to Sotiropoulos et. al. 2003.) The classification was based on six indicators: economic development, working-class mobilization, the influence of Catholic teaching on policy, the absolutist and authoritarian legacy, features of the revolutionary process, and transitional impact.

Overview of sample countries

The Netherlands

The evolution of social security systems in the Netherlands started slowly at the beginning of the 20th century, but by the 1970s the coverage of social security had extended significantly. Abram de Swaan (1988, 214–215) pinpoints the off beam focus of the political struggle. Consistent pressure for social legislation was lacking because the political concern was with the organization of social relations in the country. On the other hand, this pre-war effort to organize industrial relations paid off in the 1950s. Workers, employers and 'crown members' created a consultation system that helped to build social security systems.

The Netherlands is part of the 'continental regime' where family, civil society and the public sector provide welfare together. In the Netherlands, municipalities carry the responsibility for welfare, but most of the services are provided by private or voluntary associations. (Kosonen 1995, 58.)

Birgit Pfau-Effinger and Birgit Geissler (2005, 35) see the Dutch welfare state as a 'mixed' welfare regime that has social-democratic, liberal and conservative features. The main reason is the restructuring of family policy where partners share childcare in the dual breadwinner model. Individualism and egalitarianism seem to be values that differentiate it from the corporatist or conservative continental model.

Germany

The German welfare state has a long tradition beginning from Bismarck's era. Abram de Swaan (1988, 187–189) argues that the nationwide compulsory insurance scheme against income loss is the core that has survived two World Wars, National Socialism, and foreign occupation. In 1988, he saw it as the foundation of the West German welfare state, and later it seems to have maintained this role in unified Germany. In Germany, just like in other countries that adopted compulsory insurance schemes before 1900, the initiative came from authoritarian regime, not the workers' movement. According to de Swaan, the main factor that facilitated social policy reforms was the weakness of the petty bourgeoisie.

In Germany the state controls social security and functions as the last resort. Obligatory private insurances cover financial security and health care. Families and voluntary organisations are mainly responsible for taking care of children, the disabled, and the elderly. (Kosonen 1995, 58.)

Greece

The historical heritage of Greece, especially from the era of Ottoman rule, associates the country with Latin American countries such as Argentina and Chile (Marinakou 1998, 235–236). Maria Marinakou (1998, 240) highlights the importance of emigration which served as the mechanism for decreasing unemployment and silencing the demands for social protection. The economic importance of emigration both for the families and the country's balance of payment must be remembered as well. Marinakou (1989, 231) argues that the Greek welfare state was not founded until in the 1980s

with increases in social expenditure, the creation of the national health system, and the strengthening of social security. At the moment Marinakou (1998, 231) characterises the welfare state in Greece as semiperipheral, referring to the country's position in world economy and to the special features of Greek society which give rise to a distorted version of Keynesian welfare state.

Marinakou (1989, 241) lists several factors that have affected the development of the Greek welfare state. In the 1980s, more than 40 per cent of the active working population of Greece was employed in agriculture and small industry. Secondly, state and civil society operate in terms of clientelistic networks instead of class organisations. Thirdly, the trade union movement is to a high degree subordinated to party politics and thus a long-term planning of social policies is lacking. And fourthly, the local government has not been an important welfare provider and never achieved political and financial autonomy.

Spain

Tejero and Torrabadella (1999, 135–137) situate the origins of the Spanish welfare state project to the years 1960–1975, the last period of Franco's dictatorship. Spanish economy was liberated and the social security system was developed. Social security was tightly connected with employment. In Catholic Spain, family was seen as the core unit of society, and women's place was mainly within the domestic-familial sphere. Since then Spain has undergone social, economic, political and cultural changes. The family relationships have changed as well when Spain has moved towards democracy from authoritarian rule. According to Tejero and Torrabadella, the conservative ideal of family affected the family policies still in the 1990s, when support to families and public expenditures on the family were within the lowest in Western Europe.

Italy

Maurizio Ferrera (1996) sees Italy as an example of a Southern welfare model. He points out four characteristics that are typical of welfare systems in Mediterranean countries. Firstly, the income maintenance system is highly fragmented. Some groups are protected while others are totally excluded from the benefits. According to Ferrera and Gualmini (2000, 188–189), the system built between the late 1940s and the late 1970s is a mix of the general welfare and male breadwinner based models. The system favours males working in the core sectors of the labour market and their families. In addition to secured wages, the benefits include unemployment benefits and old age pensions. Secondly, Ferrera (1996) points out that the National Health Services are based on universalistic principles, while other parts of the welfare system are corporatist. Thirdly, the welfare sphere is not dominated by the public actors and institutions, but private entrepreneurs have a major role. And finally, the system has preserved some clientilistic features so that for example distribution of cash subsidies is selective and based on 'patronage machines'. Thus the families are not only important as a source of welfare resources, but also as a passageway to public welfare.

Slovakia / Czech Republic

In the ideology of the social state, the subsequent transition after the end of Czechoslovakia in Slovakia has been less extensive than in the Czech Republic. On the other

hand, the better economic situation of the Czech Republic has ensured better possibilities to finance social expenditures. (Kosonen 1995, 95.)

Hungary

Social security funds are governed by the state but representatives of trade unions and employers. (Kosonen 1995, 93.)

Hungary is the only former Eastern bloc country which had a system of unemployment benefits prior the transition. (Kosonen 1995, 94.)

Bulgaria

The welfare services developed during the communist era in Central Eastern European countries were more comprehensive in comparison with the systems in Greece or Spain for instance. However, services had problems with quality and equality. (Sotiropoulos et. al. 2003, 657.)

Bulgaria and Romania belong to the group of South-East European countries with particular characteristics during the transition period. They had a low GDP per capita, low level of industrialization and a large agricultural sector, and weak institutions, and they were economically dependent on the export of for example raw materials. It is also important to note that the former communist cadres remained in power in both countries until the mid-1990s. Sotiropoulos et. al. emphasize that there was a noticeable gap between official discourse and actual developments regarding social welfare in Romania and Bulgaria. In Deacon's typology from the year 1992, Bulgaria and Romania belong to the post-communist conservative corporatist type. They continued to share a commitment to socialist values after transition. Labour unions took part in the development of welfare. Few years later, United Nations Development Programme labelled Romania and Bulgaria as 'late reformers' and World Bank as 'limited to modest reform'. (Sotiropoulos et. al. 2003, 658–670.)

In the 2000s, Bulgaria and Romania have adopted more liberal and residualist social policies. They have followed strict economic policies and adopted welfare models promoted by international organisations. Sotiropoulos et. al. (2003, 669) identify poverty as the currently most important social problem in these countries.

Romania

The transition has resulted in a growing problem of poverty. In Romania, 'second economy' has been used as an additional source of income and benefits alongside with paid work. Relatives and friends constitute a 'social economy' and bribes and exchange an 'illegal economy'. These networks are used to compensate for the shortcomings of public welfare. (Kosonen 1995, 96–97.)

In the 1990s, the Romanian economy fluctuated and the welfare policy seems to have followed these cycles. (Sotiropoulos et. al. 2003, 670.)

Lithuania / Estonia

Both Lithuania and Estonia were incorporated into the former Soviet Union and thus share a common history of social security. Jolanta Aidukate (2006) remarks that after regaining the independence in the 1990s, Lithuania and Estonia started to adapt the

ideas of market economy and democracy. However, their developments since have resulted in different models of social security. As the base of comparison, Aidukaite uses Korpi and Palme's classification from the year 1998. In Estonia, the social security system is a mix of the basic security model (flat-rate, based on citizenship or contributions) and the corporatist (earnings-related, based on occupational category) model. In Lithuania, social security also partly follows the basic security model, but does have targeted (minimum level of benefits, based on proven need) elements or programmes as well.

Austria

In Esping-Andersen's (1990, 24–27) regime model Austria belongs to the conservative and corporatist group with other continental countries. The ideology behind this model emphasizes that social entitlements are deserved through employment. As in the liberal model, social welfare is directed to proven needs. This welfare system aims at the stability of social statuses. Brigitte Unger and Karin Heitzmann (2003) analyse the options that Austria as a conservative welfare state has while facing challenges such as the pressure from international economy and the ageing society. Firstly, it can maintain its current high level of social protection. However, it would be difficult to finance the system and it would affect the position of Austria in international competition and lead to a more unequal income distribution. Secondly, in the 1970s Austria added social-democratic features to the conservative model. An example is the Keynesian macro-economic policy it started to follow. The recent challenges have forced Austria to return to Bismarck's original ideas of the welfare state where the social insurance system and family are the main factors. Thirdly, the answer to the challenges could be to cut the costs of the welfare state. This can be done with the social democratic ideas of public responsibility, benefits, and services. Alternatively, there is the liberal model of decreasing benefits and confining welfare to concern only people with low income or in poverty. Unger and Heitzmann argue that Austria tried for a long time to follow the first option, ignoring the external challenges. When this became impossible, various reforms were implemented. The strongest tendency was to go 'back to Bismarck' and the roots of the conservative welfare model.

Statistical overview of the research data

The materials of this research consist of the questionnaire (Appendix 2) that was sent to all European Countries by EASPD. EASPD has members in 24 different countries. The questionnaire was originally formed in FAIDD, and EASPD used its organization to spread it to members. Later on, EASPD gathered the materials and in some cases translated original texts. One of the aims was to get information from non-English-speaking countries. There was also a special interest in official and unofficial references and documents, legislation, statistics, reports, researches, and articles in the questionnaire dealing with the de-institutionalisation process by FAIDD.

Informants were asked to perform searches in the internet, electronic databases, and libraries or by other means suitable for this purpose. About 30 keywords were given to informants by FAIDD.[1] 5–10 most important documents were asked to be translated into English from each country, especially main results, abstracts and discussions. However, the original documents of these most important documents were requested to be added to the materials in the native languages as well. In the questionnaire, the

background information of the informants (positions, roles, organizations) as well as contact information was filled in, too.

Further still, the staff of EASPD headquarters performed several searches in the internet to find information on de-institutionalisation in Austria, Belgium, Czech Republic, France, Germany, Hungary, Italy, Portugal, Romania, Slovakia, Spain, and the Netherlands. The amount of work of the staff has been huge, and the task was demanding, difficult and time consuming because the data on the subject are hard to find as they are scattered without clear indications, and moreover it is hard to find the ones that are really dealing with the issue.

The data were received from 18 countries altogether. Countries as well as and type and amount of documents are shown in the following table:

Type of the Data						
COUNTRY	**Questionnaire**	**Text**	**Statistics**	**Net reference**	**Contact message**	**Other information**
Austria	1					
Belgium				1		
Bulgaria	1	1				
Cyprus						1
Czech	1	1		1		
Estonia	1	1				
France				1		
Germany	1	3		1		
Greece	1	1				
Hungary	1	1		1		
Italy	1	1		1		
Lithuania	1	12				
Netherlands	1	3		1		
Portugal				1		
Romania			1	1		
Slovakia	1	1		1		
Spain	1	1		1		
Sweden		4			1	
Total	12	30	1	11	1	1

Total of 18 countries are represented, and 12 questionnaires were received by email. The 'text' column refers to varying materials including articles, official information, reports, information on the situation of the country involved, governmental information etc. (total 27). Lots of statistical facts were sent by Romania (statistics from other countries are included also in the questionnaire). These statistics dealt mainly with orphanages and childcare hospitals.

Websites of policy makers, organizations and actors in the field of de-institutionalisation were attached (total of 12 references). However, statistical information and legal issues were covered here too. Cyprus sent information stating that there is no population in large institutions to be de-institutionalised.

1 Keywords: Social and health policy of deinstitutionalization, decentralization, social support, sex , age, family, socioeconomic status, rural/urban housing services, supported living arrangements, community based services, empowerment, inclusion, staff attitudes, staff fears, community support and integration, societal change, trends of institutionalization/deinstitutionalization, treatment of disabled individuals, controlling policies and practices, leisure, everyday life, quality of life, independent living, community based services.

The process of gathering the data has been difficult for a number of reasons. First, the data are not easy to access. Documents are stored in different databanks and sites. They appear in formally and substantially vastly varying disguises. There is no standardized method to be used (substantially), and it creates lot of pressure on the expertise of the informants. Materials are highly selective and therefore one must be careful to draw any dramatic conclusions on the basis of documents presented here.

The Responses to the questionnaire are shown in the following table.

Questionnaire references							
COUNTRY	**Legislation**	**Report**	**Book**	**Research**	**Article**	**Statistics**	**Total**
Austria		1	6	3	17		27
Bulgaria	3	5					8
Czech	13	15	3	3*	13		47
Estonia	3	3	3	2	8		19
Germany		1			4		5
Greece					8		8
Hungary	4	1	7	1		2	15
Italy	x	x	x	x	x	x	Missing
Lithuania			2		11		13
Netherlands		4		1			5
Slovakia		4	1			1	6
Spain	2	1	9	1	6		19
Total	25	35	31	11	67	3	172

* in DVD-format

These twelve countries can be divided into three categories: former post-socialist or communist countries in Eastern Europe, the European Continent or Central European Countries, and Mediterranean or Southern European Countries. The Finnish issue of de-institutionalisation is looked at in several on-going studies at the Finnish Association on Intellectual and Developmental Disabilities.

As noted, the aim is to analyse the process of de-institutionalisation and its effects in 12 European countries. The research data are collected by means of the questionnaire. One of main focuses of the research is to ask which groups have been affected mostly by the process. Moreover, what kind of interests, differences and conflicts can be found?

In analyzing the materials, content analysis and a special matrix of analysis were used. Full table of themes can be found in Appendix 1. There, also literature references, focus points of reference, level of analysis (individual, group, organizational, institutional, national) and a short description of outcomes and field or discipline of the reference can be found.

Conclusions

De-institutionalisation is a societal process which has been one of the major ideological, cultural, political and economical forces shaping care and custody in Europe during the last few decades. However, the process is in many ways a multidimensional and even controversial issue. In this report we have studied de-institutionalisation in Europe by means of a literature review and meta-analysis of data in non-English-speaking countries. The aim of the analysis of the data available was to find out what the main groups of people are in the midst of the process, what the overall phase of the process in Europe is, and what kind of contradictions come up in the process in different countries.

On the basis of our analysis we have divided our materials into three "zones": Eastern, Central and Southern Europe. These "zones" represent different phases of the process in view of historical, societal, cultural, and economical factors. To start with Eastern European Countries, they represent a situation where old traditions and norms meet guidelines of shaping the economy according to principles of current developments of capitalism under the umbrella of European Union's integration. Of course countries are in different stages, they are not a bundle; instead of unification there are big differences between countries and even inside one country, too - that is to say, between countryside and cities, as well as between counties and regions in a given state. This goes for Southern and Central European Countries, too. In general, Eastern European Countries are largely building basic infrastructure by closing large institutions and opening smaller units. In connection with this construction of basic knowledge management, know-how of professionals is in the agenda. Centralised bureaucracies and practices often meet ideologically very different soil concerning the subjective rights of people in need and citizenship of a new era. In the following table there are, in a nutshell, core themes of the data available.

Bulgaria

Groups: Children

Process: Building infrastructure for de-institutionalisation; legislation, education of professionals, infrastructure, "narrowing institutional entrance, widening the exit of specialised institutions"

Contradictions: Resources of Social State, formation of Civil Society, Cultural contradictions e.g. client centredness; polito-economically between centralisation and de-centralisation; Governance vs. individuality

Czech Republic

Groups: People with disabilities

Process: Improving care and structures for de-institutionalisation, training of professionals, quality of services, "social inclusion as ideological frame"

Contradictions: Institutionalised practices vs. client orientation, Cultural lag and Governmentality as obstacles

Estonia

Groups: People with intellectual disabilities; people with disabilities

Process: Building infrastructure for de-institutionalisation, improvement of services and education of professionals, growing client orientation in practice

Contradictions: One-sidedness of services, attitudes, problems of infrastructure, rapidly enlarged market economy vs. balanced improvement of social state

Hungary

Groups: People with disabilities

Process: Building of infrastructure for de-institutionalisation (small scale homes), "residential institutions for people with disabilities should gradually, but by January 1 2010 at the latest, be transformed so that those with lower support needs can live in small-scale group homes, and people with more severe disabilities, if they need it, should receive humanized and modernized institutional care. Knowledge management, statistical information, humanization of care

Contradictions:
Lack of proper infrastructure, ideological obstacles, Citizenship of people with disabilities, conditions in residential care/in community

Lithuania

Groups: People with disabilities, children

Process: Building of infrastructure

Contradictions: Funding, lack of infrastructure, ideological contradictions

Slovakia

Groups: People with disabilities

Process: Transformation of social services, Mental health policy, values, norms, attitudes and know how for better care, infrastructure, "big institutions are against human rights"

Contradictions: Lack of infrastructure, cultural and ideological issues, governance of services

Southern Europe

In Southern Europe, the Mediterranean Countries' cultural struggle for de-institutionalisation has a relatively long history. Moving away from big institutions and towards community has been a major challenge. This has meant struggle for the rights of the individual to live his or her life as an active member of community and society. The transformation has also meant changing the role of patients and the disabled in community and the meaning of illness and handicap. The difficult task of the process has been and is now that the process is not only a cultural but always an economical and a social question. The main problem is that people's needs are not only cultural but they need proper resources in community. Limited growth of the social state and "giving it back to families"-policies have had very severe implications for individuals, families and relatives. Modernization and economics create contradictions and pressures upon traditional family-models and traditional ways of caring people in community. Shift to postmodern era services, organized by professionals within community, is still in its formative phase. How to combine the cultural heritage of de-institutionalisation process with economics with adequate social state and support is a crucial question. Again the most important features of the data are presented in the following table.

Greece

Groups: Disabled persons, People with psychiatric persons, minors,

Process: Fostering community care, building infrastructure in community, Giving up admissions to institutions

Contradictions: Cultural conflicts in community (attitudes for exclusion), lack of resources in community and outside large institutions.

Italy

Groups:
People with mental illness, Psychiatric patients, children/adolescents

Process:
Building of appropriate service system in community, fulfilment of Law 180/1978 still underway

Contradictions:
Cultural conflicts in community, political contradictions, lack of resources in community, economical burden on families and individuals

Spain

Groups: People with intellectual disabilities; people with disabilities, people in situation of dependency

Process: Subjective rights of persons in situation of dependency, building infrastructure for community care

Contradictions: Serious lack of resources in community, services, infrastructure, cultural dispute of social inclusion, economical base of services

Central Europe

In Central or Western Europe de-institutionalisation has been going on for some twenty years. Normalisation, integration and living in community have been slogans of the process. New elements and developments have now been subjective rights and individuality. However, in spite of improvements in the quality of life, a lot remains to be done. The cultural process is still on its way in a substantial manner. Everyday life outside institutions is a challenging matter reaching the point where to combine autonomy and responsibility and fulfilment of individual needs. The process has also shown the complexity of organizing the help in community. Staff members in social services are often complaining that there are not enough resources to work with, and that organizational hindrances and bureaucratic obstacles sometimes make work in community a laborious job. Ideologies and hegemonies are slow to change, as are routines and practices stemming from old ways of acting. Economic base of social state and transformation of care are at hand. Privatisation and budget cuts are the main direction at a time when individual needs are more abundant than ever. Citizenship, subjectivity, and recognition of the individuality of people in a real manner is very demanding task. Nevertheless it is reported that de-institutionalisation has had positive impacts on lives of the people transferred to community although this phenomenon includes multidimensional ambivalences.

Austria

Groups: People with intellectual disabilities, people in psychiatric institutions

Process: Integration, normalisation and quality of life in community, individuality

Contradictions: Improving the quality of life in community, citizenship, subjective rights vs. economical restrictions

Germany

Groups:
People in community care, people with mental problems

Process: Developing community care, quality in community care

Contradictions: Services in community for people in need, economical base of services, cultural norms, values and attitudes

Netherlands

Groups: People with mental disabilities, people with disabilities

Process: Emancipation and self-determination of people in community care, developing system based on individual needs

Contradictions: Efficiency and productivity claims vs. developing community care, cultural values and societal norms

APPENDIX 1 COUNTRY TABLES

Austria

Title	Bernhard,J..; Hovorka, H. & Schaffranek, W.: "Normalisierung. Zur Entwicklung integrativer, Wohn- und Lebenszusammenhänge geistig und mehrfach behinderter Menschen in Österreich. (1991)
Type	Book
Level	National/case studies
Focus	The book portrays the efforts undertaken in Vienna to create "integrative" residencies for people with intellectual disabilities from 1978 to 1991. First a couple of studies on normalisation and Community-based living undertaken by the ISD (Institute for Social Design). from 1979 to 1987 are described. A model for creating a principle of normalisation is highlighted as one of the major outcomes. A research on the "1000 Wohnplätze"-program, a project of Vienna-municipal and the consortium of Viennese service-providers (ARGE Wohnplätze) to create 1000 new domiciles for people with intellectual disabilities. The key points of this research were the principles of normalisation and integration as well as the quality of staff. For that purpose, qualitative interviews and also questionnaires were conducted with staff-members.
Target group	People with intellectual disabilities.
Result/Outcome	Schaffraneck highlights that social contacts between inhabitants rather take place on a technical level. The task of integration has barely been realised. The inhabitants often wish to live in settings with less care than provided by organisations. Also staff members complained about a low level of communication between living-units and management of service providers. The level of education of staff varies, with limited possibilities for further training. Positive elements include apartments, the accomplishment of the amount of new residencies, and the achievement of real integration. A negative conclusion was the fact that the 1000 new places were by far not enough (demand being 5000 places). Also the self-determination of inhabitants was on a poor level, the staff had low qualifications for the jobs, and above all: people with challenging behaviour had to stay in large institutions.
Theoretical/ideological/practical standpoint	Research on inclusion and community living

Title	Kreilinger, B.:"20 Jahre Leben in der Psychiatrie" (2002)
Type	Book
Level	Individual case study
Focus	The single case study deals with the process of reconstructing the biography of a woman with intellectual disability who lived for more than 20 years in a psychiatric hospital in Vienna. Based on the theoretical concepts of "romantic science" (Lurija), feminist research, and "Rehistoriesierung" (Janzten), Kreilinger conducted 16 interviews with her.
Target group	People in psychiatric institutions
Result/Outcome	The research approach would be called "inclusive research" and, as such, is unique in Austrian research on deinstitutionalisation so far. The life story focuses on three phases: life before institution, in psychiatry, and after deinstitutionalisation. Through the eyes of a concerned person, lived experiences of institutionalisation and deinstitutionalisation are made visible: punishment, friendship, resistance in the asylum as well as the challenges of moving out and living in the community.
Theoretical/ideological/practical standpoint	Individual experiences of institutionalization and deinstitutionalisation

Title	Schmidt, R.: "Die Paläste der Irren. Kritische Betrachtungen zur Lebenssituation geistig behinderter Menschen in Österreich." (1993)
Type	Book
Level	National
Focus	The author's aim is to provide an overview of the present situation of people with intellectual disabilities in Austria in the year 1993. The paradigms of normalization and integration are presented and then placed in the context of deinstitutionalisation. A historical retrospective of Austrian social policies and attitudes towards people with intellectual disabilities is provided.
Target group	People with intellectual disabilities.
Result/Outcome	Certain continuity is pointed out: persons who were responsible for the mass murder of people with intellectual disabilities in the 30s and 40s influenced the "Heilpädagogig" and psychiatry in post-war Austria very significantly. Focus on the Austrian psychiatry reform of 1993 and the beginning of deinstitutionalisation is described in two hospitals. There is a positive change in progress, but some deficits still exist.
Theoretical/ideological/practical standpoint	History and present day of institutionalisation and deinstitutionalisation.

Title	Neubauer, G. & Theunissen, G.: "Aus der psychiatrie in die Gemeinde. Zur Enthospitalisierung von Menschen mit geistiger Behinderung in Österreich" (1999)

Type	Article
Level	National
Focus	Authors give a short historical retrospective of the deinstitutionalisation movement in Austria. They also provide an analysis of an extensive research project called "Enthospitalisierung". One of the aims was to achieve an overview of the state of the process of deinstitutionalisation.
Target group	People with intellectual disabilities.
Result/Outcome	Results show that from 1991 through 1997 the number of people with intellectual disabilities living in psychiatric hospitals was reduced from 1038 to 318. The size of the community residences of the persons who left the hospital due to deinstitutionalisation ranged from 2 to 161 inhabitants (average size 22 persons). The principles of normalisation, self-determination and integration were broadly implemented according to caretaker's self-assessment. Nevertheless deficits could be identified concerning sub domains of the above-named principles: contact with other neighbourhood residents, access to adult education programs, and some domains of self-determination. In conclusion, living in a community setting does not necessarily lead to social integration and participation. On a regional level the efforts towards deinstitutionalisation were put into practice most effectively in Voralberg, Tirol and Vienna.
Theoretical/ideological/practical standpoint	Research on deinstitutionalisation

Title	Berger, E.; Hochgatterer, P., Leithner, K.; Maryschka, Ch. & Grassl, R.: "Die Reintegration behinderter Menschen durch Ausgliederung aus psychiatrischen Einrichtungen - das Wiener Deinstitutionalisierungsprojekt." (2006)
Type	Research
Level	Institutional/local/regional
Focus	From 1997 through 2001 the last people with intellectual disabilities moved from psychiatric hospitals to community based living in Vienna. This was the last step in a process declared in 1979 but not put into effect until 1986. The retrospective part of the evaluation study deals with the shift 1987 between 1997 and then the period from 1997 to present. The empirical part of the study is focused on "characteristics", psychiatric assessment, and quality of life of the deinstitutionalized persons (n=181).
Target group	People with intellectual disabilities.
Result/Outcome	Findings show that after leaving hospital, quality of life improved especially in the areas of privacy and access to community based infrastructure (public transport, supermarket, coffee house). Psychopathology did not increase during life in the community. In conclusion: Viennese deinstitutionalisation regarding aspects of organisation and contents was very successful.
Theoretical/ideological/practical standpoint	Evaluative research on deinstitutionalisation

Title	Lingg, A.: "Geistig behinderte Menschen in der Valduna 1862-1995. Chronik, Enthospitalisierung, Katamnese." (1998)
Type	Article
Level	Institutional/local
Focus	History of the psychiatric hospital Valduna in Voralberg from 1862-1995 is described and it is reflected in the context of the "patients" with intellectual disabilities.
Target group	People with intellectual disabilities.
Result/Outcome	Originally Valduna was a monastery (1391-1782). In 1862 it was transformed into "Wohltätigskeit- und Landesirrensanstalt", and 24 years later 133 mentally ill and "feeble minded" persons lived there. During the Third Reich it served as a military hospital. In the course of a euthanasia program, 247 "mentally ill and feeble minded" persons were deported to a concentration camp near Linz. Some managed to return to their families or were relocated to Swiss home-residencies and therefore survived. After WW II it was reopened as mental home. During the 50s and the first half of the 60s, the institution had to face several problems concerning the structural status of the buildings as well as personal resources. The Austrian reform of psychiatries lead to a constant deinstitutionalisation of long-term patients beginning in the end of the 1970s. In 1985, 56 persons were asked about their quality of life. Psychopharmalogical medication could be reduced in most cases. Social integration was not established as effectively as had been assumed. . 29 % of the neighbourhood residents showed a positive attitude towards the deinstitutionalised people, most were indifferent, and some negative reactions were reported. The second study was conducted in 1997. 25 people had mild and moderate intellectual disability, and 2/3 of them showed severe intellectual disability. None of those with severe disability were returned, and only 28 % of the other population were returned to Valduna. In conclusion: referring to objective parameters, life has improved for the deinstitutionalized persons with intellectual disabilities.
Theoretical/ideological/practical standpoint	History and evaluative findings of deinstitutionalisation.

Title	Österreichisches Komitee für Sozialarbeit: "Leitbilder zum Wohnen geistig behinderter Menschen in Österreich" (1987)
Type	Booklet
Level	National
Focus	In the brochure, community based living-models in Austria are presented. It was compiled by a consortium of Austrian experts working on innovative models for living units for people with intellectual disabilities. This work can be seen as a commitment to integration, normalization and deinstitutionalization of Austrian service providers.
Target group	People with intellectual disabilities.
Result/Outcome	A model for creating living units referring to paradigms of normalization and community based living is provided. Those living units are all connected with each other, and persons are assigned to a group home or single-living-unit on the basis of their abilities: the centre of these units is represented by a group home for residents with severe or profound intellectual disabilities, who need permanent care. This unit is linked to smaller group homes for persons who need a moderate level of ambulant care and also to single-living-units for independent inhabitants.
Theoretical/ideological/practical standpoint	Deinstitutionalisation and model for community living

Bulgaria

Title	"The Child Protection Law"(2002)
Type	Legislation
Level	National
Focus	The Child Protection Law defines eight basic functions of the State Child protection Agency, further elaborated in the Statutory Rules of the latter. The Agency stated following priorities for its work in 2002: 1) Prevention of child abandonment; development of alternative care forms, deinstitutionalisation, and better quality of institutional care, 2) prevention of violence, 3) building a national information system., and 4) elaboration of a National Plan for Training and Qualification of Childcare and Child Protection Workers.
Target group	Children
Result/Outcome	For the successful implementation of state policy directed at the prevention of abandonment and deinstitutionalisation, updating the information about children in specialised institutions regularly is of utmost importance. SCPA carried out a national survey on the condition of these institutions in the year 2001. The conclusions are: 1) The deinstituionalisation process has not yet really started due to the lack of alternatives to institutional placement. Percentage of children placed in specialised institutions has not decreased in 2001. The total number of children in all institutions for the year 2001 is 31 102. It comprises 1.93 % of Bulgaria's child population (out of 1 607 505). In 1999, the number of children in institutions was 34122 (1.78 %). 2) Institutional entrance is still wide open, mostly due to the lack of co-ordination between the Child Protection Law and statutory rules of separate Ministries regulating the placement of children in specialised institutions. 3) Only adopted children and a small number of children who came back to their biological family have real exit from institutions. There is no guarantee of reintegration though. 4) For children remaining away from their families, the creation of alternative care forms as close to family environment as possible is imperative.
Theoretical/ideological/practical standpoint	Research on children in institutions, social and health policy

Title	"A new Structure will assist the Process of Taking Children out of Institutions" /Social Support Agency/UNICEF (2007)
Type	Report
Level	National/local
Focus	In compliance with an agreement between the Social Support Agency and UNICEF Bulgaria, a new Technical Department will be founded within the structure of the agency. It will assist the deinstitutionalisation process on both national and local levels. Department's primary aim will be that of helping forward the process of social inclusion. The latter will be realised by building an effective system of alternative community social services, with the purpose of taking children out of institutions and directing them to the system of services. The specific objectives of the new structure include: creation of a co-ordinating mechanism for the interaction of all national and local participants in the process; elaboration of a proposal for a system of standards concerning community social services directed towards deinstitutionalisation, including financial ones; application of the "money follows child" rule. While establishing the needs assessment system for local social service users, services which assist the process of taking children out of orphanages and shelters will be emphasised.

	The permanent team of the Technical Department includes a supervisor and two administrative assistants, with the temporary collaboration of short-term consultants and foreign advisors.
Target group	Children
Result/Outcome	The UNICEF programme for Bulgaria will aid the TD financially for three years. The achievement of operational targets and programme goals, TD's functioning and realisation of planned activities will be overseen by the consultancy group composed of representatives of specialised administrative sectors within the SSA, the SCPA, the National Association of Municipalities in the republic of Bulgaria and UNICEF. The SSA guarantees the TD access to all "Child Protection" departments for the purpose of providing them with methodological and technical support in planning social activities and services promoting deinstitutionalisation. The TD is a temporary structure planned to function for 3 to 5 years, or until its goals concerning deinstitutionalisation are achieved.
Theoretical/ideological/practical standpoint	Provision of social services/practice of deinstitutionalisation
Title	"The Process of Deinstitutionalising children from orphanages and shelters." (2006)
Type	Report on Ms. Silvia Tsanova, vice-executive-director of SSA.
Level	National
Focus	The Deinstitutionalisation Process is compound of several elements. The first one is narrowing institutional entrance. Second aspect is widening the exit of specialised institutions.
Target group	Children
Result/Outcome	There have been a lot of problems in the past 3 years. Three points: Staff selection, a long way to a high professional level of childcare; Funding and material provision; Training and Project work. Children have benefited from deinstitutionalisation in all regards: social, psychological, material, economical, and the provision of community services. The process of deinstitutionalisation is expected to speed up due to EU funding and shared experience.
Theoretical/ideological/practical standpoint	Interview on Process of Deinstitutionalisation
Title	"National strategies for social protection and social inclusion on the republic of Bulgaria for 2006-2008 year" (2006)
Type	Report
Level	National
Focus	Development of alternative social services; implementation of efficient social protection; equal access and opportunities for personal development of children and people with disabilities; improvement of the quality of institutional care; narrowing the entrance of institutions (prevention) and widening their exit (reintegration) - these are the main objectives of the government's conception for deinstitutionalisation of specialised facilities for children and social facilities for adults with disabilities.
Target group	Children/people with disabilities
Result/Outcome	The document describes a mechanism of restructuring, reforming or closing down facilities for children and adults with disabilities. Joint local committees will assess specialised institutions with reference to criteria which take into account: the location and accessibility of each one of them, material conditions, quality of care, individual care, opportunities for social integration and adaptation. Committees can recommend a rapid closing of institutions that score under the required minimum of points. For those that pass the evaluation, a development plan will be drafted in cooperation with their staff. The development of alternative care forms is underlined as a condition for real deinstitutionalisation to be carried out.
Theoretical/ideological/practical standpoint	Development of social services
Title	Development of alternative social services is a base for de-institutionalisation of specialised institution for children and people with disabilities./Ministry of Labour and Social Policy (2006)
Type	Report
Level	National
Focus	The policies of social protection and social inclusion in Bulgaria are considered to be an indivisible part of general state policy. Specific strategies, programmes, and measures are being implemented in each separate area of this policy (including deinstitutionalisation). Each of these contributes to achieving the objective of improving social protection and inclusion of society's vulnerable groups.
Target group	Vulnerable groups in society/citizens

Result/Outcome	In the last few years Bulgaria has advanced in tackling the problems of poverty and social inclusion by applying the new model of social policy - namely connecting the latter with other public policies. This has helped the transition from passive to active social protection aimed at creating human resources, material and social capital, realised among other means by active involvement of vulnerable groups in increasing their own well-being. The approach focuses on the causes of negative social trends like poverty and social exclusion rather than on their consequences.
Theoretical/ideological/practical standpoint	Social policy
Title	"In December 2006 13 specialised wagons for passengers with limited mobility will be launched together with new train schedules." / Ministry of Labour and Social Policy (2006)
Type	Report
Level	National
Focus	This is one of the measures realised in accordance with the Action Plan of Equal Opportunities of People with Disabilities for 2006-2007.
Target group	Passengers of limited mobility
Result/Outcome	Access remains one of the heaviest problems faced by the people with disabilities.
Theoretical/ideological/practical standpoint	Transportation/Accessibility of services
Title	"The Social Support Law and its Statutory Rules"
Type	Legislation
Level	National
Focus	This law defines the order, conditions and organisation of social services. Social services are based on social work and directed at assisting the everyday activity and social inclusion of persons. These services are provided following personal preference and choice. Community social services include: personal assistant, social assistant, housekeeper, home social patronage, public support centre, and others.
Target group	Users of services
Result/Outcome	Despite the existing relatively good regulation and ongoing processes of decentralisation and deinstitutionalisation, institutional (in-house type) services still prevail. Community services are not yet fully developed.
Theoretical/ideological/practical standpoint	Legislation on social work
Title	"Law for the Integration of Persons with Disabilities and its Statutory Rules."
Type	Legislation
Level	National
Focus	The field of providing social services for persons with disabilities is being regulated by the law for the integration of persons with disabilities. The Integration of Persons with Disabilities arranges the social interactions and social protection related to the integration of people with disabilities, which is realised by means of social services.
Target group	People with disabilities
Result/Outcome	Social services lead to more progress in the quality of life of people with disabilities than social aid.
Theoretical/ideological/practical standpoint	Legislation on social services

Czech Republic

Title	"Conception of Transformation Support of Residential Social Services in Different Types of Social Services Provided in Community and Natural Environment of Persons with Disabilities." (2007)
Type	Legislation
Level	National/Development of Social Services in EU and the Czech Republic
Focus	Support of social service providers with the interest to offer high quality social services on professional level.
Target group	Social service providers/People with disabilities

Result/Outcome	
	The aim of transformation of institutional social care for persons with disabilities is to create a co-ordinated network of services for clients, allowing them to live in community and to minimalize the so far preferred way of social service provision within institutional social care.
Theoretical/ideological/practical standpoint	Legislation
Title	"Implementation of Quality Standards of Social Services". Guidebook for Service Providers. Ministry of Labour and Social Affairs. (2002)
Type	Report/Guidebook
Level	National
Focus	The document is based on Standards of Quality in Social Services, which summarizes what is generally expected of good services. Implementation of standards of quality. The Standards of quality have been created in the last three years in cooperation with clients and service providers. Standards concern all types of social services, which is why they are formulated generally. The work was based on EU accepted principles of social inclusion.
Target group	Workers in social services
Result/Outcome	
	Procedural standards are the most important. They specify how social services should look like, how to adjust a service to each person's individual needs. It is also aimed at clients' human rights protection. Personnel standards devote to personnel the ensuring of the service. The quality of service is directly dependent on workers - on their abilities, education, support - and on conditions that they have for providing social service. Operational standards define conditions for the provision of social services. They concentrate on the space in which the social services are provided, on accessibility and quality improvement.
Theoretical/ideological/practical standpoint	Provision of Social Services
Title	"National Report on Strategies of Social Protection and Social Inclusion for 2006-2008"
Type	Report
Level	National
Focus	National Report follows documents in the field of social protection and social inclusion from 2004-2006, mainly National Action Plan of Social Inclusion for 2004-2006. Report summarizes issues of social cohesion, struggle against poverty and social exclusion, modernization of the pension system of health and long term care. It sets up goals and tools and creates mechanisms for their successful implementation. It comes out from EU Commission, New Framework for Open Coordination of the Policy of Social Protection and Inclusion in EU (March 2006). There are 3 strategic documents: Action Plan of Social Inclusion, Pensions ad Health and Long-term Care.
Target group	Officials
Result/Outcome	3 Priority goals of Social Inclusion: 1) Strengthening of integration of socially excluded persons or persons in danger of social exclusion, elimination of barriers in entering and keeping on the labour market, 2) Strengthening of family cohesion and awareness of its importance, strengthening of awareness of solidarity among generations and of children's rights. Supporting of decision making processes on the local and regional levels and partnership development in the policy of social inclusion.
Theoretical/ideological/practical standpoint	Strategy for Social Services
Title	"Preliminary National Report on Health Care and Long-Term Care in the Czech Republic."(2005)
Type	Report
Level	National
Focus	Health Care and long-term care are assessed on the basis of three recommended principles: accessibility, quality and financial sustainability. The term refers to a wide range of supportive health and social services provided to people who are no more self-sufficient - either because of their age, disability or for any other serious reason - and thus require constant assistance by another person in coping with their everyday life and daily needs. In particular, these services include assistance with self-service, personal hygiene, housework and provision of links to social environment. The assistance can also involve help with such activities as shopping, seeing a doctor, paying the bills, taking medication.
Target group	Care givers

Result/Outcome	Long-term care seeks to ensure that these people remain involved in daily life as much as possible, receiving proper treatment in an adequate environment, even if their actual health condition would not enable them to do so.
Theoretical/ideological/practical standpoint	Health Care/Strategy
Title	"National Plan of Support and Integration of Persons with Disabilities for 2006-2009. (2005)/National Committee for Persons with Disabilities.
Type	Report
Level	National
Focus	Awareness of responsibility for the elimination of barriers obstructing the participation of persons with disabilities. That is why there have been 3 national Plans approved recently that should have contributed to improving of their status in society. Each individual chapter contains an introduction into the issue, description of the desirable target state which should be reached, and individual clearly defined measures to be used, together with the indication of responsible department and a target date.
Target group	Persons with disabilities/Care givers/Officials
Result/Outcome	These topics are covered: Education and school system, Social Security, Employment, Health Care, Accessibility of Environment, Accessibility of Information and Cultural Heritage, Prevention of Discrimination of Persons with Disabilities, Participation of Persons with Disabilities and their Organizations in Public Affairs Administration, Coordination and Monitoring of National Plan Fulfilment, and Financial Impact of Each Measure.
Theoretical/ideological/practical standpoint	Planning of services, strategy

Estonia

Title	"Rights of People with Intellectual Disabilities: Access to Education and Employment"/Open Society (2005)
Type	Research
Level	National
Target group	People with Intellectual Disabilities
Title	"Legislation of Welfare and Social Services for People with Disabilities" (1995)
Type	Legislation
Level	National
Target group	People with Disabilities
Title	"Eesti Vaimse tervise alusdokument"
Type	Legislation
Level	National
Focus	Mental Health Service System
Target group	Mental health clients
Result/Outcome	In Estonia, systems which are bound up with mental health are in principle escalating to client entered. Deinstitutionalisation is on the increase, and the pressure is on the public services. This domain needs government assistance with well advised plans. The main problem about services is one-sidedness.

Germany

Title	Maas & al: "Community Living": Bausteine fur eine Burgergesellschaft". Hamburg (2007)
Type	Report
Level	National
Focus	Report from the Community Living Congress held in Hamburg between 18 and 20 October 2006. Contains a number of articles written by German experts, with references to the situation in Germany.
Target group	People with mental problems
Result/Outcome	Situation in Germany with special reference to community living and citizenship
Theoretical/ideological/practical standpoint	Social Psychiatry

Title	Zechert, Christian: "Ensuring Quality in the Delivery of Community-Based Services" website of the European Coalition for Community Living.
Type	Article
Level	National
Focus	Presentation at ECCL's User Involvement Seminar in Zagreb on 20-21 April 2007. Contains references to the situation in Germany.
Target group	People in services
Result/Outcome	Some references to the situation in Germany.
Theoretical/ideological/practical standpoint	Community Living

Title	Miles-Paul, Ottmar: "The Need for Deinstitutionalisation and Community Living In Europe: Challenges and Achievements". Website of the European Coalition for Community Living (2007)
Type	Article
Level	National/European
Focus	Contains references to the situation in Germany and Europe
Target group	People in community living
Result/Outcome	Situation in Germany and Europe with special reference to community living
Theoretical/ideological/practical standpoint	Community Living

Title	" A National Initiative for development of community-based alternatives to institutions in Germany" (2007)
Type	Article
Level	National
Focus	Some information about the situation in Germany.
Target group	People in community-based living
Result/Outcome	Some references to the situation in Germany.
Theoretical/ideological/practical standpoint	

Title	Miles-Paul, Ottmar: "Daheim Statt Heim: New Campaign for Community Living in Germany (Unpublished)
Type	Article
Level	National
Focus	Newsletter with references to the number of people in institutions in Germany
Target group	People in Community Living
Result/Outcome	Some references to the situation in Germany and information on number of people in institutions.
Theoretical/ideological/practical standpoint	Community Living

Greece

Title	"Independent Existence Deinstitutionalisation"
Type	Article
Level	National
Focus	Deinstitutionalisation is the main objective. It is not possible to maintain the constituted policies of equal opportunities or equal treatment when there are Greek men and women who, because they live under conditions of infirmity, are led by the conditions to the incarceration to institutions.
Target group	People with infirmities

Result/Outcome	It is obvious that the suppression of institutions cannot solve anything unless conditions are created first that would ensure the decent survival of persons with infirmities in the community. It is obvious that it is up to the State to continue recognizing the responsibility for the persons with infirmities in the same way as in the case of institutions. Factual proof of recognition is the taking of part in the economic responsibility for the costs of ensuring the survival of persons with infirmities in the community. Everywhere in the Western states, corresponding policies have been established, dubbed policies of direct payments (Direct Payments). In Greece, even today, the State resists. It prefers to enclose the persons with infirmities in institutions instead of the right to live free and with dignity in a manner of their own choice. The violation of human rights in the institutions has enormous cost. Independent Existence is comparatively inexpensive, with bigger qualitative and quantitative output and of course developmental prospects.
Theoretical/ideological/practical standpoint	Independent Existence outside institutions/ conditions for Deinstitutionalisation.
Title	"Deinstitutionalisation? Which way?"
Type	Article
Level	National
Focus	Fifteen years keeps the discussion on the deinstitutionalisation. No one among the controversialists dares it. It is reported that infrastructure will make the deinstitutionalisation result as obvious. Instead of rational and argued dialogue we read and see a storm of fooleries that has nothing to do with either infirmity or with deinstitutionalisation of invalids.
Target group	People with infirmities/invalids
Result/Outcome	According to international experience, access should be given in the creation of networks of professional assistants and reproachable transports. Equally important are the initiatives that concern the Avocation, the creation of enterprises through the house, the mechanical equipment of re-establishment, and the new technologies. However, in Greece we are long away from that, and lack theoretical knowledge. We try to invent the wheel without calculating that the wheel and the re-establishment already have been discovered, and that young Greeks do not have to do less than to apply the known and achieved recipes.
Theoretical/ideological/practical standpoint	Implementing deinstitutionalisation/ conditions for deinstitutionalisation
Title	Zaharias, E.: "Reaction of Local Societies in the Deinstitutionalisation of Individuals with Mental Disturbances and in the Creation of Community Services of Mental Health"
Type	Article
Level	National
Focus	At the end of the 1980s, the process of deinstitutionalisation of individuals with chronic mental disturbances began in our country, too, at the same time with the growth of mental health services in the community such as the Centres of Mental Health, the Psychiatric departments of General Hospitals, The Day Centres, the Units of Professional Training, The Hostels, the Protected Apartments etc. Today in various parts of Greece there are community services available that offer around 3000 places of re-establishment, of which 1000 are alternative to the psychiatric hospital, housing structures (hostels, apartments). Now, organized and functioning are 45 hostels and 5 boarding schools that will accommodate 700 individuals that live in clinics. It should be noted that the 1000 individuals that already living in these housing structures and the 700 that are now being prepared to be moved, have multi-institutional experience not so much for therapeutic reasons but for reasons having to do with the social services in which they are included and accommodated. This precisely is also the reason for the residents' reactions from regions in which they function or where out-hospital services of mental health and psycho-social re-establishment have been introduced. These reactions take form of protest in local and central beginnings (municipalities, ministries) while often lead also to resorts to courts with demand their prohibition of operation. The arguments of residents, as these say in their written protests, can be categorized in two: first "well-disposed exclusion" and second "negative exclusion". A common result of these reactions in practice is the refusal of right of social rehabilitation of these individuals and consequently the refusal of their right to live a life of their own in the community from where they receive also the advisable therapeutic care in any form. These refusals spring from the prevalent social attitude of incarceration and isolating the different as "dangerous".
Target group	People with mental disturbances
Result/Outcome	The social attitudes mentioned before and perceptions of exclusion acquire particular negative importance when they are also expressed by representatives of beginnings and institutions (local self-government, juridical decisions) while they of course do not correspond with the state that draws, finances and oversees the creation of these new structures, harmonized with international scientific and institutional practice and national legal frame. It appears that in the course of the deinstitutionalisation process and the parallel growth of services of mental health and psycho-social re-establishment in the community, there is still quite a lot of resistance.

Theoretical/ideological/practical standpoint	Social attitudes against deinstitutionalisation and for exclusion
Title	"The Place of ESAEA with regard to in the Planning and Concretisation of National Drawing Deinstitutionalisation" (2005)
Type	Article
Level	National
Focus	Beginning with the admission that in Greece in the 21st century there cannot exist individuals with infirmity that would live in situation of social incarceration in the institutions. The need of configuring a frame of policy priorities for one of the most sensitive sectors of social policy, deinstitutionalisation, becomes imperative.
Target group	People with infirmities
Result/Outcome	The training of national planning of deinstitutionalisation should include action which is supported in two pylons: 1. in the rearrangement and redefinition of structures of closed care that exists and entertains individuals with infirmity and 2. in the development of a supporting frame which will ensure the care of individuals with heavy infirmities and multiple needs of dependence in the community.
Theoretical/ideological/practical standpoint	National social policy for deinstitutionalisation
Title	"The Psychiatric Reform Needs Urgently…Psychiatrist"
Type	Article
Level	National
Focus	The model of Deinstitutionalisation as applied in Greece is "in the air". The infrastructures (centres of mental health, hostels, boarding schools etc.) that are essential in order that they receive care afterwards their exit from psychiatric hospital "they have sprouted" fragmentarily and without planning, in certain regions of the country.
Target group	People with mental disturbances
Result/Outcome	Suggestions for what could be done: creation of a big number of alternative structures, that is to say community psychiatric services. There is a need for 80 centres, centre per 100-120 000 individuals. Today only 24 centres are in operation. The organisation of clinics in general hospitals. The foundation of 1900 places in hospitals, Day Centres. Deinstitutionalize 3000 chronic insiders in nine psychotherapy hospitals. Evident is the fear with professionals of mental health that the application of the psychiatric reform for the deinstitutionalisation of patients will happen in the country as it happened also in the USA in 70's during Ronald Reagan's presidency.
Theoretical/ideological/practical standpoint	Evaluation of deinstitutionalisation.
Title	"Deinstitutionalisation should be supported"
Type	Article
Level	National
Focus	The regulations that concern incarceration in correctional shops lead to inhuman unfairness at the expense the minor concerning being in effect for the adult detainees and they lead to cancellation of more lenient treatment the minors.
Target group	Minors
Result/Outcome	The complete abandonment of the Service of Commissaries of Minors from the state castigated and question of is strengthened the institution of foster's minors and are facilitated the families that they become foster families, so that is supported the institutionalisation of minors.
Theoretical/ideological/practical standpoint	Deinstitutionalisation of correctional institutions
Title	Kritikos, Y. "Refills the cuckoo nest"
Type	Article
Level	National

Focus	Psychiatric clinics even refill with patients, from those that were deinstitutionalized after the state is unable to ensure them the care that they need, in order that they remain outside the "clinics". At the same time the 370 hostels where they were founded in order to materialize the deinstitutionalisation, sub function and those who bear still with shingled personnel and a lot of debts, tend to be shifted to new "small shelters". In forgotten psychic clinics the workers submit even deaths of patients which have simultaneously some urgent pathological problem and were led to general hospitals where they cannot be treated well.
Target group	People with psychiatric problems
Result/Outcome	The human solution through the ambitious program Psychargo began 23 years ago to be developed progressively with locomotion of patients from the sordid conditions of psychiatric hospitals in modern hostels, boarding schools, protected apartments and centres of day. Hardly had begun to attribute the effort, reaches in 2005 and 2006 that the government not only did not increase the financing but decreased a lot of the chalk lines that do not suffice more they cover despite only the 30 % of expenses. The danger of interruption of operation of units is henceforth direct and it is continued this situation shortly tens of units will close with result the mental patients return measly in psychiatric clinics and experience again situation institution and social exclusion.
Theoretical/ideological/practical standpoint	Comments on the deinstitutionalization process

Hungary

Title	"Act XXVI of on the Rights and Promoting Equal Opportunities of People with Disabilities."
Type	Legislation
Level	National
Focus	The purpose of the act is to coordinate (align) national legislation with international treaties and recommendations, most importantly with UN and Council of Europe documents. With reference to the Hungarian Constitution, the act reinforces equal rights and opportunities, independent living and active participation of people with disabilities.
Target group	People with Disabilities
Result/Outcome	The Act creates the National Programme for Disability Affairs which should be adopted by the Hungarian Parliament at regular intervals - usually every 6 years - and report on its implementation every 2 years. The relevance of the Act for deinstitutionalisation is that it declares that "residential institutions for people with disabilities should gradually, but by January 1 2010 at the latest, be transformed so that those with lower support needs can live in small-scale group homes, and people with more severe disabilities, if they need it, should receive humanized and modernized institutional care".
Theoretical/ideological/practical standpoint	Legislation

Title	"National Programme for Disability Affairs 2007-2013"
Type	Legislation
Level	National
Focus	The document lays down the strategic objectives of disability policy up to 2013.
Target group	People with disabilities
Result/Outcome	Regarding residential services and deinstitutionalisation, it states the following: "The number of places in small group homes are accessible for all groups of people with disabilities. The regulations for small group home care for people with disabilities must be reviewed, which includes the conditions for access and the professional contents of the services provided. Attention is to be paid to making sure that the new form of care be spread nationwide. The size of boarding institutions be limited to a maximum of 40 people." (EU, European organizations of people with intellectual disabilities, inclusion Europe, European Disability Forum).
Theoretical/ideological/practical standpoint	Strategic planning/legislation

Title	"Act III of 1993 on Social Administration and social assistance and 1/2000 (January 7)"/Ministry of Family and Social Affairs Regulation on Personal Social Services
Type	Legislation
Level	National
Focus	These legal acts regulate the scope and conditions (physical conditions, staff, services etc.) of personal social services for people with disabilities.
Target group	Officials/Care givers/ People with Disabilities

Result/Outcome	The types of services are: long term care group home, rehabilitation group homes, day care, domiciliary care. Group homes are facilities accommodating 8-12 people, under certain conditions up to 14 people. Supported accommodation or small homes are virtually non-existent.
Theoretical/ideological/practical standpoint	Provision of social services/legislation
Title	"Yearbook of Social Statistics 2004". (2006)
Type	Statistics
Level	National
Focus	The Central Statistical Office publishes yearly statistics on social care, including residential care for people with disabilities.
Target group	Officials/People with disabilities/Public
Result/Outcome	Data include number of services, number of places, staff, providers etc.
Theoretical/ideological/practical standpoint	Statistical information
Title	"Institutional Survey of the 2001 Population Census."
Type	Statistics
Level	National
Focus	Summary and data tables of the institutional survey of the 2001 Population Census.
Target group	Officials/People with Disabilities/Public
Result/Outcome	In addition to basic statistics published yearly, this is a more in-depth survey with data on location of facilities, age, infrastructure, beds/room, characteristics of residents.
Theoretical/ideological/practical standpoint	Statistical information
Title	"From Dependence to Autonomy" (Ed. by Zaszkaliczky, Peter. (1998)
Type	Book
Level	National
Focus	This book is a collection of papers presented at the joint conference of Kezenfogva and Soros Foundations in 1997. These are the two organizations that promoted deinstitutionalisation.
Target group	Citizens/People with Disabilities
Result/Outcome	This volume gives a good general overview of the origins of deinstitutionalisation and community-based provision in the late 1990s in Hungary.
Theoretical/ideological/practical standpoint	Promoting of deinstitutionalisation

Italy

Title	"The Deinstitutionalisation"
Level	National/local
Focus	"After two years only after the approval of the Law 180/1978 concerning the closure of the lunatic asylum, some doctors attacked the anti-psychiatric ideology, soaked with cultural annihilation, negation of mental illness and unfair attribution of guilt to the families. Families carried the cost of those ghastly mistakes above all. The promoters of Act 180/78 still affirm that "the law is good, but it has been politically sustained. Anyhow a law cannot be valued on the basis of so-called good intentions."
Target group	Mental patients/people with mental illness

Result/Outcome	
	"Since the beginning, the programmes of the Centres have been disastrous, or rather, several Centres started their activities with futile rehabilitation projects, without taking proper responsibility for the patients discharged and those coming from the country-side. This economically based policy has enabled the closure of the hospitals, thereupon discharging the most severe patients or transferring part of them in often inadequate structures: all the care expenses will rest on the families' shoulders in a shameful way. For some, the deinstitutionalisation has been a considerable failure whose consequences were easy to foresee.
Theoretical/ideological/practical standpoint	Evaluation of the process of deinstitutionalisation
Title	"Children and Adolescents In The Institutes for Under Aged"
Level	National/local
Focus	"The process of deinstitutionalisation suffers from the lack of data of its global entity that obfuscates, in some way, even the same identity and therefore, at last, its regulation. Moreover the activation of the interventions needed as a benefit of the children is often compromised. The present day of the institutionalised child often hides the past that should emerge from the shadows, expecting a future that corresponds to his/her needs, taking into account an extra remarkable improvement even about the information process. The aforesaid is needed in order to identify and follow the development of each individual history both through supporting pathways and supplies given by services, finding out the aspects of continuity, coherence and integrity."
Target group	Children/Adolescents
Result/Outcome	Therefore the attempts of regulating the know-how of the infancy and adolescence policy impact whose proposal is the evaluation of the outcomes of the interventions, seem to be innovative. The reform action introduced to overreach the charities institutes for minors still has some risk factors, over all due to the necessity of developing a particular knowledge on the actual layer of disposability and offer of the alternative forms of guardianship provided for by the law that precedes and steers the decisions of both the services and juvenile judiciary.
Theoretical/ideological/practical standpoint	Needs of care for children in institutions
Title	"Rehabilitation As For Deinstitutionalisation"
Level	National/local
Focus	The goal that carries on the rehabilitation programme is connected with the process of deinstitutionalisation that means the opportunity to gain access to infinite relations and exchanges. From that perspective, rehabilitation can be considered a particular intervention available even in an early phase together with, but not after or otherwise, the therapy treatment. On the other hand rehabilitation is meant as an instrument turned against the permanence of trapping niches, such as: isolated families, ghettos, segregation slums, sheltered care sites not properly used and so on. One of the main tasks of rehabilitation is to promote mental health, as it has to utilize social sources. Among other important goals is the need to introduce the concept of "social network". In the social network, what is significant is the quality of the relationship set up between a particular resource and the person, such as: the conflicted areas, the areas in which exchanges are possible, which are the behaviours "expected" in that situation.
Target group	People in rehabilitation
Result/Outcome	Unfortunately in many cases during these years within the social network, only a mapping of the country has been done, giving a privilege to the research more easily visible on the side of the institutions, comparing to the analysis of the factors connected with the quality of life of a person. Under this last point of view quality of life is the result of the negotiation that starts from needs satisfaction.
Theoretical/ideological/practical standpoint	Rehabilitation and the deinstitutionalisation

Lithuania

Title	"The law supplemented by new provisions on racial and employment equality" (2007)
Title	"Minimum wage increased to 700 litas" (2007)
Title	"Youth policy has been implemented in Lithuania for 10 years already" (2007)
Title	"State pensions for those who took active part in gratuitous donation" (2007)

Title	"Education of parents and the public about IT threats would help better protect children, shows public opinion poll" (2007)
Title	"Social statistic"

Netherlands

Title	Van Loon: J.Arduin: "Van zorg naar ondersteuning" (2006)
Type	Research
Level	National/local institution
Focus	Ten years ago, on January 1st 1996, Arduin became an independent organization. For the former institute "Vijvervreugd", childcare centre "Akka" and outpatients clinics dagbestedning for elderly people "de Windroos", a new vision on living and working was developed. The emancipation and self-determination of people with mental disabilities became the main principle to work with for the improvement of quality of life. J.Van Loon did his PhD. research on this theme.
Target group	People with mental disabilities
Result/Outcome	First the problematic situation in the starting period of Arduin is discussed, as well as the role of educational science, the research question, and the reason to opt for action research. Further the background and developments in view of the change process in Arduin are made explicit and those dimensions of quality of life that can be seen as most essential in the renewal are worked out: inclusion, self-determination, and personal development. The fundamental changes in the thoughts about these people are being elaborated. The main focus is on the question which kind of support a person needs in order to have a better life. The choices Arduin made in consequence of the process with most fundamental choice dismantling the institute are defined. Also the differences between quality of care and quality of life to support people with mental disabilities are addressed. Arduin is presented as an example of how an organization made the transition from quality of care to quality of life. Further research concerning the quality of medical care in Arduin and a research project in which the model of supported living is realised for a woman with intensive support needs are discussed. Finally several evaluative researches on clients, parents/relatives and employees are summarized. A discussion and conclusion complete this dissertation.
Theoretical/ideological/practical standpoint	Action research on deinstitutionalisation

Title	RMO: "De handicap van de samenleving: over mogelijkheden en beperkingen van community care".(2002)
Type	Report
Level	National/societal
Focus	There is much vagueness concerning the concept of community care. It is about people with long-term disabilities and about the support these people might need. One important although vague aspect concerns the hypothesis that community care has something to do with replacing the support from institutions by support from the society. The council points out that it does not support this view. According to RMO, community care is to be seen as an instrument to realise the quality of life of people with disabilities. On this view, a person is first and foremost a citizen, and then sometimes a patient or client. As citizens, people with disabilities participate in the society as much as they are able to. This means that the society in turn must be accessible, useful and achievable. To realise this, some aspects of the society need to change.
Target group	People with disabilities
Result/Outcome	The council states that strong community developments are in contrast with the concept of community care. The developments include the efforts to perform the strive for efficiency and high productivity. Therefore there are again separate solutions offered to people with disabilities: adjusted transports, special education, and protected working areas. In other words there is no thought of "inclusion". This has led to an impasse: community care meets contrary aspects in the society that cannot easily be changed. Still the changing of these trends will eventually be inevitable, especially looking at the proportional rise in the ageing population. As long as the impasse exists, it is of great importance that policies for people with disabilities are characterized by differentiation: they should be adjusted in all areas of life to the individual situation of these people. In doing this (experience) knowledge (for a great part to be activated) must be drawn on. The direction belongs to the local authorities. While the problems are so complex and contain many areas of policy, most local authorities are inadequately equipped to do this. The committee can, in collaboration with the Union of Dutch Municipalities, advise local authorities at their task. In the long run further work on a legal basis on which people with disabilities can rely is needed. In the Law of Equal Treatment Chronically Ill and Disabled, experience can be gained. The legal basis can be reinforced in the future by designing a Law on social participation with which people with disabilities can receive participation allowance comparable with for example child allowance. Existing personal budgets can be included in that.
Theoretical/ideological/practical standpoint	Deinstitutionalisation and development of community care.

Title	Beraadsgroup Community Care: "Leven inde lokale samenleving" (1998)
Type	Report
Level	National
Focus	In 1997, following a request from the State Secretary of Healthcare, Welfare and Sports, the Council Community Care was launched. The state secretary was confronted with an abundance of desires from the care for people with mental disabilities, of which many had a short-term character. The advice from the CCC provides a clear change of perspective for the sector. It pays attention to the possibilities to increase social participation with people with (mental) disabilities. The main questions in the advice are: "What kind of life should people with severe mental disabilities lead? Are they passive receivers of care and services or do they actively control their own life? Should they be treated as a group or is an individual approach possible? Where should people with mental disabilities live? Should they live near other people or somewhere else?
Target group	People with mental disabilities
Result/Outcome	The CCC thinks it is necessary that people with severe (mental) disabilities have more possibilities to actively control their own life and live "normally". The council points out three policy strategies: 1) making the society co-responsible for the care and support of people with severe disabilities; 2) giving people with a long-term disability - or their representatives - the tools in hand by which they can have more influence on care, accommodation, education, work, or in other words, their live; 3) transforming the sector in such a way that flexible support is offered at places where people with disability wish, without this leading to a fragmentation of the expertise that has been built over the years.
Theoretical/ideological/practical standpoint	Implementing and lines of Community Care

Title	RVZ: "Samen leven in de samenleving" (2002)
Type	Report
Level	National
Focus	Community care and community living. When it comes to people with disabilities, community living and community care are increasingly important starting points for the policy set out by the government. Community living means that people with disabilities live and participate in the society. In the case of community care, the necessary support is embedded in that society.
Target group	People with (mental) disabilities
Result/Outcome	Community care is a choice, not a dogma. The choice between community care and institutional care is one everyone needs to make for themselves. It will depend on individual wishes and needs, local possibilities and financial consequences. When community care is available as an alternative for institutional care, intake in institutions will gradually decrease for those for whom the available support is not sufficient. Financial aspects: Research in order of the RVZ shows that on the macro level, community care is neither more nor less expensive than institutional care. Bottleneck: lacking development. Community care is still in its infancy. Although there are promising experiments, the development is lagging behind the expectations. Healthcare. The healthcare for people with mental disabilities is also in need of improvement. The government. According to the RVZ responsibility for community care should lie with the national government. On the local level this means municipalities. Law of antidiscrimination: The legal grounds on which community care is based according to the RVZ is the law of equal treatment for the handicapped and chronically ill. The Government: On the national level the responsibility for community care should lie with the ministry of Home Affairs and Royal Relations (BKZ). Care and welfare: On this area the RVZ recommends a simplification of two new laws: a renewed healthcare insurance and a new services law.
Theoretical/ideological/practical standpoint	Principles and experiences of community care.

Title	Evenhuis, H.M. "Want ik wil nog lang leven" (2002)
Type	Report
Level	National
Focus	This publication contains the background study of professor dr. H.M. Evenhuis: "Because I want to live long with the advice. Living together in the community". Evenhuis makes visible which bottlenecks are present in the care for people with mental disabilities.
Target group	People with mental disabilities

Result/Outcome	First, the (genetic) cause of the mental disability is often unknown. As a result it is not possible to act pro-actively on medical area, and practitioners are insufficiently capable of looking for complications coming from this cause. It can be seen that institutions for people with mental disabilities are catching up on this. A second problem is that many women with mental disabilities are wrongly ignored in population research concerning cancers. As a result, breast cancer and uterine cancer are discovered at an advanced stage, which significantly reduces the chances of recovery. The third problem addressed is that most g.p.´s and other medical professionals in the regular care have insufficient knowledge and expertise of mental disabilities. When looking at the increasing de-institutionalisation, this more and more becomes a problem. The council is under the impression that incompleteness in the care for people with mental disabilities should not obstruct the developments of community care.
Theoretical/ideological/practical standpoint	Research findings of bottlenecks in the care of people with mental disabilities/The developments of community care.

Slovakia

Title	"National Strategies report on social protection and social inclusion for 2006-2008"
Type	Report
Level	National strategy for social inclusion following articles 136-137 of Amsterdam Treaty and Lisbon summit/EU
Focus	Intention to emphasize connection between social inclusion and social protection
Target group	People with disabilities
Result/Outcome	Improvement of social inclusion in order to increase accessibility and quality of social services so as enlarging community based services.
Theoretical/ideological/practical standpoint	Preparing a new law about social services/Social policy

Title	"The place and role of Christian social service providers in the process of decentralisation and transformation of social sphere" (2003)
Type	Conference Report
Level	National
Focus	Transformation of social services
Target group	Citizen/user and social service provider
Result/Outcome	The number of inhabitants in one resident institution is an important indicator of the possibility of social inclusion. The high number of users practically eliminate the chance to use individual approach treatment
Theoretical/ideological/practical standpoint	Big institutions are against human rights. Reformation of social policy and health policy. Quality of services.

Title	"National strategies report on social protection and social inclusion for 2006-2008."
Type	Report
Level	National
Focus	De-institutionalisation and development of community based services
Target group	Users of mental health services
Result/Outcome	Creating enough community-based services, which will better react on individual's needs. Care programme approach: 1) Systematic detection of social and health needs of people with severe mental health problems, 2) individual planning, 3) provision of case-manager, and 3) regular changes of individual plan according to the person's needs; based on multidisciplinary collaboration.
Theoretical/ideological/practical standpoint	Mental health policy, reform of values, attitudes, learning and know-how /WHO Declaration on mental health in Europe.

Title	"Decentralisation in Slovakia/Balance-sheet of never ending story 1995-2005" (2006)
Type	Book/author Niznansky, Viktor
Level	National
Focus	The author describes the strategy, conception and evolution of decentralisation in Slovakia during 10 years.
Target group	Citizens

Result/Outcome	
	The principles of the reform are: civic society, transparency, effectiveness, subsidiary; flexibility. Regional development is analysed, decentralisation should be a tool to change trend. Decentralisation has given power to regions. Voices of citizens are also presented.
Theoretical/ideological/practical standpoint	Organizing of services, governing.

Title	"Statistics on gender mainstreaming"
Type	Website/statistics
Level	National

Title	"Introduction and Development of Community based Rehabilitation (2001-2004)" (2004). "Canadian International Development Agency - CIDA"
Type	Project Report
Level	National/Governmental/NGO/
Focus	One of the focuses was to support creating partnerships within partners from regions and communities to improve social inclusion by improving connections between social and health services, which are better focused on people's needs and which are more sensitive to their specific needs. 3 main areas: 1) Developing two centres of good practice with well-trained staff, 2) educating several professionals in community based services, who will be able to create teaching materials, and who will educate other professionals, 3) teaching materials, an educational program in community-based learning for professionals, people with disabilities, their families and students, 4) organizing meeting of professionals on the international, national and regional level focused on increasing public awareness of the issues.
Target group	People with disabilities
Result/Outcome	CBR main features include partnership, community involvement, empowering, and focusing on one's abilities rather than disabilities. Change of attitudes and behaviour towards disabilities in the community. Empowerment of people with disabilities to become accountable for their own lives and decisions. Shared awareness of community based rehabilitation. Improving functional independence of people with disabilities. Introducing technologies suitable for people with disabilities. Pro-active role which should be taken by people with disabilities, and/or special needs and their family members and other community members as well.
Theoretical/ideological/practical standpoint	Community care/rehabilitation,

Spain

Title	"Law of Promotion of the Personal Autonomy and Attention to the People in Situation of Dependency" (2006)
Type	Legislation
Level	National
Focus	Law of Promotion of the Personal Autonomy and attention to the People in Situation of Dependency is approved in Spain. This law supposes a substantial advance in the responsibility of the Administration for the dependent, since it will recognize subjective rights, and will guarantee the basic conditions and the contents common of the attention of the National System of Autonomy and Attention to the Dependency.
Target group	People in a Situation of Dependency
Result/Outcome	In the catalogue of benefits and services that are contemplated it is possible to emphasize the recognition and support to the figure of the caretaker, as well as the reinforcement of the resources that are alternative to residential institutionalisation. The paper of family receives special focus in the new Law setting an existing debt by the care of its dependent relatives.
Theoretical/ideological/practical standpoint	Legislation on Personal Autonomy and Attention to the People in Situation of Dependency.

Title	FEAPS: "Housing and residence for people with mental retardation – guide for quality" (2001)
Type	Book(let)
Level	National
Focus	This booklet tries to be an instrument for the planning and organising of different solutions of housing for people with intellectual disability (independent houses, supported apartments, group houses, residences…)
Target group	Providers of Services/People with intellectual disability.

Result/Outcome	Provides propositions to good practices, proportions for the good working of services, rights of the users, a guide for management process, and a "view to the future". It also encloses some relevant documents.
Theoretical/ideological/practical standpoint	Planning and Organizing Services
Title	"Law on Equal Opportunities, no Discrimination and Universal Access for People with Disabilities." (2003)
Type	Legislation
Level	National
Focus	This law highlights concepts concerning non-discrimination, positive actions and universal accessibility.
Target group	People with disabilities
Result/Outcome	It aims at guaranteeing and recognising people's right to equal opportunities in all areas through the progressive and gradual introduction of accessibility in all environments, products and services.
Theoretical/ideological/practical standpoint	Legislation on equal opportunities
Title	FEAPS:" Guide for the intervention with people with intellectual disability who are within the prison system." (2006)
Type	Book(let)
Level	National
Focus	This booklet tries to guide in the treatments with prisoners with intellectual disabilities.
Target group	Providers of services/People with intellectual disabilities in prisons
Result/Outcome	In a system where institutionalisation is not a personal choice, this publication describes the procedures used with this collective, with the aim to guide the associations which want to start with this intervention, describer the user's profile, his needs, unify techniques of intervention.
Title	FEAPS: "Disorders on the Mental Health of People with Intellectual Disabilities" (2007)
Type	Report
Level	National
Focus	This report tries to analyse the situation of people with intellectual disabilities and mental health disorders in Spain.
Target group	People with intellectual disabilities
Result/Outcome	The report shows some figures (95 % of people with intellectual disabilities and mental health problems do not receive medical attention) and highlights the need of actions in the Spanish health system. It also proposes the minimum services needed in Spain: 5 integrated centres of evaluation and treatment, 22 residences, and 54 outpatient departments.

APPENDIX 2 QUESTIONNAIRE

EASPD
IMPROVING SERVICES
IMPROVING LIVES

Questionnaire

Literature review on
De-Institutionalisation
In all European countries

Luk Zelderloo (Secretary General)
Diletta Dischinger (Membership and PR Officer)
☎ +32 2 282 46 10
🖷 +32 2 230 72 33
✉ info@easpd.be
💻 www.easpd.org

Content

Introductory remarks

De-institutionalisation is very high on the agenda of EASPD since many years. Through seminars and studies, EASPD and its membership is trying to understand the process and to make it accessible to all interested parties.

At the same time the Finnish Association on Intellectual and Developmental Disabilities (FAIDD) has received funds from its authorities to do a study on de-institutionalisation across Europe. The aim is to collect information about deinstitutionalization for research purposes by collecting reasonable material like formal and informal documents, statistical data, research publications and other reports etc.

Due to a language barrier it is not possible for the Association to gather documentation in all national languages but rather mainly only in English which limits the information gathering. Therefore, part of the research on de-institutionalisation in national languages was entrusted to EASPD.

This exhaustive literature review will then be made available on the EASPD website to strengthen the process of de-institutionalisation & the development of Person Centred Services and Community Based Settings.

a) Method

The study will be done in all European countries.

To do the study electric databases or the internet can be used to search publications or other informative documents on de-institutionalisation with the help of keywords translated into the national language. The idea is to get information on non-English publications and other documentations.

Secondly after having found a list of publications/documentations by using electric search robots, guided library search or some other method, the 5-10 most important search results that include relevant information on deinstitutionalization and disability should be identified.

Thirdly after having selected 5-10 most important search results the essential parts of this material should be translated into English, like abstracts, summaries, conclusions etc. to get an overview on the issue. The translated material and original selected search results should be sent to EASPD. Email attachments and internet links are recommended, but paper prints are possible too.

b) Purpose of the questionnaire

The present questionnaire is an important tool to gather input for this study. The purpose of the questionnaire is to facilitate the information gathering and the analysis of the information.

c) Structure of the questionnaire

The questionnaire is divided in 3 parts:

1. Personal and organizational details of the expert

2. General literature review
3. Summaries of the 5-10 most important documents

For the general literature review, may we ask you to use the normal format to indicate documents:

Book:
Author's last name, first name. *Book title*. Additional information. City of publication: Publishing company, publication date (ISDN nr. If available)

Magazine & Newspaper Articles:
Author's last name, first name. "Article title." *Periodical title* Volume # Date: inclusive pages.

Website or webpage:
Author's last name, first name (if available). "Title of work within a project or database." *Title of site, project, or database*. Editor (if available). Electronic publication information (Date of publication or of the latest update, and name of any sponsoring institution or organization). Date of access and <full URL>. Note: If you cannot find some of this information, cite what is available.

In order to facilitate your work, the questionnaire is structured around pre-defined text boxes and/or to tick boxes. You can move from one text box to another by using the cursor or the TAB-keys. The text boxes can be extended, which means that you may insert (write or paste) as much text as you want.

d) Organisation of replies

Available for the study are 2 month from the moment the questionnaire has been sent and a formal commitment exists with the counterpart. Remuneration for the work done will be negotiated with each partner. The final date for the study is September 2007 by which the Finnish partners will need all results of the study in all countries.

e) Key words and types of documents

Social and health policy of deinstitutionalization, decentralization, social support, sex (or gender!?), age, family, socioeconomic status, rural/urban housing services, supported living arrangements, community based services, empowerment, inclusion, staff attitudes, staff fears, community support and integration, societal change, trends of institutionalization/deinstitutionalization, treatment of disabled individuals, controlling policies and practices, leisure, everyday life, quality of life, independent living, community based services

- Legislation
- Research
- Statistics
- Reports
- Books
- Magazines or articles

1 . Personal and organisational details of the expert

Organisation

Name of the organisation in national language (*full name and abbreviation*)	
Name of the organisation in English	
Type of organisation	

Address

Street	
Number	
Area Code	
Town/City	
Country	
Website	http://

Expert

Name	Mr. ☐ Mrs. ☐	
Position		
Telephone	++	
Mobile	++	
Fax	++	
E-mail		

2. General Literature review

Please provide an exhaustive literature review on the topic of de-institutionalisation in your country
Please select the type of document in the drop down menu under the heading select!

Book	
Book	
Magazine or Article	
Magazine or Article	
Magazine or Article	
Magazine or Article	
Magazine or Article	
Report	
Report	
Legislation	
Magazine or Article	
Magazine or Article	
Magazine or Article	
Legislation	
Legislation	
Report	
Book	
Research	
Research	
Select	
Select	
Select	
Select	
Select	
Select	
Select	
Select	
Select	
Select	
Select	

3. Summaries in EN

Please provider summaries in EN for the 5-10 most important documents and send in attachment the original document in the national language.
Per summary max. 1 page!

Title 1:

Summary:

Title 2:

Summary:

Title 3:

Summary:

Title 4:

Summary:

Title 5:

Summary:

Title 6:

Summary:

Title 7:

Summary:

Title 8:

Summary:

Title 9:

Summary:

Title 10:

Summary:

***** Thank you for your time! Please send this questionnaire back to EASPD HQ info@easpd.be.*****

Literature

Aidukaite, Jolanta (2006) The formation of social insurance institutions of the Baltic States in the post-socialist era. Journal of European Social Policy 16(3), 259–270.

Anttonen, Anneli & Sipilä, Jorma (1994) Viisi sosiaalipalvelumallia. Eurooppalaisten hyvinvointivaltioiden vertailua sosiaalipalvelujen näkökulmasta. Janus (3), 226–248.

Castoriadis, Cornelis (1998) Imaginary Institution of Society, MIT, USA.

Corden, Anne & Duffy, Katherine (1998) Human dignity and social exclusion. In Sykes, Rob & Alcock, Peter: Developments in European Social Policy. Convergence and diversity. The Policy Press, Bristol, 95–124.

Elias, Norbert (2000) The Civilising Process (3rd edition), Basil Blackwell, Oxford.

Eräsaari, Risto (1995) Hyvinvointivaltion muodonmuutos. In Eräsaari, Risto & Rahkonen, Keijo (eds.): Hyvinvointivaltion tragedia. Keskustelua eurooppalaisesta hyvinvointivaltiosta. Gaudeamus, Helsinki, 167–188.

Esping-Andersen, Gøsta (1990) The Three Worlds of Welfare Capitalism. Polity Press, Cambridge.

Ferrera, Maurizio & Gualmini, Elisabetta (2000) Reforms Guided by Consensus: The Welfare State in Italian Transition. West European Politics 23 (2), 187–208.

Ferrera, Maurizio (1996) The 'Southern Model' of Welfare in Social Europe. Journal of European Social Policy vol 6. no 1, 17–37.

Foucault, Michel (1991) Discipline and Punish. Harmondsworth, Penguin Social Sciences.

Goffman, Erwin (1970) Asylums. Harmondsworth, Penguin.

Julkunen, Raija (2001) Suunnanmuutos. 1990-luvun sosiaalipoliittinen reformi Suomessa. Vastapaino, Tampere.

Julkunen, Raija (2006) Kuka vastaa? Stakes, Helsinki.

Kosonen, Pekka (1995) Eurooppalaiset hyvinvointivaltiot. Gaudeamus, Tampere.

Kuusterä, Kirsti & Teittinen, Antti (2008) Angloamerikkalaisen deinstitutionalisaatiotutkimuksen aiheista. Julkaisematon artikkelikäsikirjoitus.

Lewis, Jane (1992) Gender and the Development of Welfare Regimes. Journal of European Social Policy 2 (3).

Marinakou, Maria (1998) Welfare states in the European periphery: the case of Greece. In Sykes, Rob & Alcock, Pete (ed.) Developments in European Social Policy. Convergence and diversity. The Policy Press, Bristol, 231–247.

Pfau-Effinger, Birgit & Geissler, Birgit (2005) Care and social integration in European Societies. The Policy Press, Bristol.

Rose, Nikolas (1999) Powers of Freedom: Reframing Politcal Thought. Cambridge: Cambridge University Press.

Saari, Juho (2003a) Johdanto. Saari, Juho (toim.): Instituutiot ja sosiaalipolitiikka. Johdatus institutionaalisen muutoksen tutkimukseen. Sosiaali- ja terveysturvan keskusliitto ry, Helsinki, 5–18.

Saari, Juho (2003b) Eurooppalainen hallintatapa ja sosiaalipolitiikka. In Saari, Juho (ed.) Instituutiot ja sosiaalipolitiikka. Johdatus institutionaalisen muutoksen tutkimukseen. Sosiaali- ja terveysturvan keskusliitto ry, Helsinki, 175–204.

Social Security Programs Throughout the World: Europe 2006 (2006) Social Security Administration, Washington DC.

Sotiropoulos, Dimitri A., Neamtu, Ileana & Stoyanova Maya (2003) The Trajectory of Post-communist Welfare State Development: The Cases of Bulgaria and Romania. Social Policy & Administration 37 (6), 656–673.

de Swaan, Abram (1988) In Care of the State. Health Care, Education and Welfare in Europe and the USA in the Modern Era. Polity Press, Cambridge.

de Swaan, Abram (1990) The Management of Normality: Critical Essays in Health and Welfare. Routledge.
Tejero, Elisabet & Torrabadella, Laura (1999) Family Relationships in Democratic Spain. In Chamberlayne, Prue & Cooper, Andrew & Freeman, Richard & Rustin, Michael: Welfare and Culture in Europe. Towards a New Paradigm in Social Policy. Jessica Kingsley Publishers, London and Philadelphia, 132–150.
Unger, Brigitte & Heitzmann, Karin (2003) The Adjustment Path of the Austrian Welfare State: Back to Bismarck? Journal of European Social Policy 13 (4), 371–387.

Kehitysvammaliitto
Viljatie 4 A, 00700 Helsinki
Puh.: (09) 348 090
Faksi: (09) 3853 398

http://kehitysvammaliitto.fi/julkaisut/tutkimusjulkaisut

ISSN 1797-0474
Helsinki 2008