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DISCIT

Making Persons with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable European Social Model

Deliverable 6.1 (D6.1)

Comparative analysis of the current state of affairs in community living

Review of statistics, law, policy and research on deinstitutionalisation and community living for persons with disabilities

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Work Package Leader:	**Jan Šiška, Charles University, Czech Republic**
Contact person:	**Jan Šiška, jan.siska@pedf.cuni.cz**
Project URL:	**www.discit.eu**

Abstract

The United Nations Convention of Rights of Persons with a Disability (UN CRPD), Article 19, states that supporting disabled people to live in the community as equal citizens is an issue of human rights. The segregation of disabled people in institutions is a human rights violation in itself. In addition, living in the community is a key pre-requisite for active citizenship.

This report draws on templates completed by local researchers for each of the 9 participating countries - Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK. It also draws on other international reports and research literature with the aim of describing the current situation of people with disabilities in each country and across Europe more generally, with a particular focus on community living as active citizenship. Templates included information on the current living situation of people with disabilities, the policy and systems to promote community living for people with disabilities, and the experiences of people with regards to the core elements of active citizenship.

Overall there have been considerable developments in last decade towards community based support for people with disabilities, but with substantial progress still needed. In some countries institutional provision is still the main form of provision, especially for those with more severe disabilities. In all countries services for more than 30 people on one site still exist although in Norway this is for only a very few people with multiple and profound physical disabilities (e.g. following an accident) and in Sweden only in the form of acute services for people with mental health problems. Even in countries where the process of closing the older hospitals has completed, a trend towards re-institutionalisation has been reported. In terms of active citizenship little information exists in most countries about the experiences of people with disabilities and however the information that does exist indicates that people with disabilities (especially those with more severe disabilities and in particular those with intellectual disability) have little choice over where they live, with whom they live and who supports them. They experience lack of freedom even within their own homes and lives and often do not receive the support needed to support their inclusion in their local communities. People with disabilities still face disadvantages in terms of employment and access to community facilities, despite policies that exist to ensure equal opportunities and access.

In conclusion, there is still a need to convey clearly the concept of community-based living and the framework of the UN Convention. Challenges to active citizenship for people with intellectual disabilities include issues such as the mistranslation of the CRPD, the state of the nation financially and politically and associated limitations in spending on social services, and a lack of progressive mental capacity legislation. The introduction of direct payments, personal budgets or personal assistance were seen as facilitative for active citizenship but have not always resulted in any significant improvement and, contrary to expectations, did not always result in a decline in the number of people requesting places in institutional services. In addition in most countries, even in Norway and Sweden, these systems are only really an option for those with less severe disabilities. Only in the UK are personal budgets and personal assistance regularly accessed by people with more severe disabilities. The key factor identified from the research in determining the quality of people's lives was the approach and skills of staff who are supporting them. This has important implications for the training of staff who are supporting people to live in the community.

Contents

Introduction

Living in the community (as opposed to an institution) is a central part of active citizenship. However one conceptualises active citizenship, whether in terms of 'Security' (Exercising both rights and duties; reciprocity and complementarity of the individual's and the community's responsibilities), 'Autonomy' (Exercising freedom of choice; taking responsibility for one's own future and risk-protection), 'Influence' (Exercising co-determination, individually or collectively, participating in self-organised, voluntary and political activities & in civil society), or a mixture of all three, being a part of society physically as well as conceptually, is critical to its achievement. The segregated, isolated nature of most institutions makes this very difficult and in many cases impossible.

The international legal framework sets out the right of disabled people to live in the community. The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), which came into force in May 2008, recognises this right through Article 19, which entails the provision of "a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." The Convention obliges states to develop community living that will replace institutional care through a process of 'progressive realisation'. This requires states to take measures to the maximum of their available resources with a view to achieving progressively the full realisation of the rights involved. They must, therefore, move in the direction of realising the rights of disabled people but they are allowed to do so at a rate determined partly by the resources available to them.

Work Package 6 analyses developments towards community living related to a broader set of policy issues and discourses in the nine selected countries. This report is an outcome of the Task 6.1. The aim of the task is to review and synthesise existing studies of, or official statistics on, community living and the role of community care services in Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK. The team reviewed existing national literature and evidence provided by the national researchers. The synthesis is to form the basis for developing an analytical framework for understanding of the group's interaction with the social services and other welfare providers.

Methodology

Existing sources of data were reviewed by each partner to identify and collate relevant material. The type of data collated included (where possible) prevalence of disability in the countries, number of people in residential establishments, policies and systems supporting deinstitutionalisation and the development of community based support; the current living situation of people with disabilities; information on choice of living situation and support; information on how active people were in their community and the policies and systems available to support their active engagement in their own lives and in their local community.

A template was provided to each local researcher with brief guidelines on the type of information that should be extracted where available. The aim was to have data from each country in as consistent a form as possible to facilitate the synthesis. Data provided was examined to assess, as far as possible, its internal consistency and any inconsistencies between different sources. Where possible and where time allowed, any gaps or missing sources where followed up with the informants in each country. In order to ensure accuracy of the process, the work package leader consulted on the development of the template, collation of data, the overall completeness of data and the final reporting with Dr. Julie Beadle Brown from Tizard Centre, University of Kent, UK. The primary sources of information were the templates provided by each country but the knowledge of those completing the synthesis was also used to fill in gaps where possible.

Number of people with disabilities

Availability and completeness of data

Review of national data showed that there were no existing sources which would provide a comprehensive picture about the number and characteristics of provisions for people with disabilities in the countries studied. The general availability of data is uneven within and between countries. Only Ireland has a national register covering people with intellectual disabilities and people with physical and sensory disabilities, including the services they access, although by its nature this is limited to those known to services. In the UK the Learning Disabilities Public Health Observatory brings together statistics on the numbers and needs of people with learning disability and service users data. In most countries official statistics come from the Department of Work and Pensions (or equivalent) and often includes people with long-term health conditions such as diabetes, epilepsy etc in addition to those with the type of disabilities of interest here. Some data are drawn from people receiving benefits, for example in the UK. In some countries such statistics are based on self-report. Other sources of data come from local authorities or municipalities and as such, this sample is usually based on those who use services. In countries like UK or Germany there were difficulties in bringing together data from different regions or states.

Prevalence of disabilities

Table 1 reports the prevalence of disability. The data were provided by the national statistical offices, central departments or research reports. The prevalence of disability varies in the countries from 4.8 % in Italy, 15 - 17 % in Norway and 19 – 21 % in UK. In Sweden and in Norway data referring to prevalence of disability were self reported (15.5 %). However in Italy it was recognised that the official statistics are an underestimate and that the European Union estimated that prevalence of disability in Italy should be around 16% of the population.

In some countries data on prevalence of different types of disabilities data are available and in some countries data on intellectual disability were included. In Norway 0.45 % of the population has an intellectual disability, in the Czech Republic it is 1%, in Ireland 1.3%. For Germany, Italy, UK and Switzerland the data on type of disability is either not available (Germany, Switzerland, UK) or provides information only about percentage of people with physical and sensory disability (Italy). The overall availability of information is rather patchy and incomplete. Wide variation of prevalence of disability as well as the availability of data is likely to reflect national practices in terms of both counting and diagnosing disabilities (e.g. whether they are using DSM, ICF or other systems to diagnose different disabilities).

Table 1 Prevalence of disabilities of general population where available and type of disability as a percentage of population of people with disabilities as indicated.

	Any disability	ID	PSD	Mental health	Other groups
Norway	15-17%[1]	0.45% of gen pop.	70% of those with a disability had pain or movement disorders 7% sensory	12% of those with a disability had a mental health condition	
Sweden	15.5%[2] - self-reported 32%[3]		30% (of 15.5%) – mobility problems 5.8% visual impairment 11% hearing impairment	20% (of 15.5%) (severe 0.48%)	
UK	19 - 21%[4]	2% of pop.[5]			
Czech Rep.	10% of population[6]	1%	5.2% physical 1.6% sensory	1.2%	“internal 5%”
Serbia	7.9%[7]		Visual 3.3% Hearing 2% Physical 4.7%		Memory/concentration 1.34% Problems with independence 1.23% Communication 0.81%
Ireland	13%[8]	9.7%[9] of people with disabilities 1.3% of general pop.	3% [10](represents 55% of PSD population)		
Germany	8.9% of population with severe disability[11]		64% with severe disability had physical disability		
Switzerland	15% 6.73% severe				
Italy	4.8% [12] EU estimate - 16%		2.3% > 6 years physical 1.1% > 6 years with sensory		

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[1] Norwegian Labour Force Survey Disability Supplement 2011 (adults)

[2] Self-reported levels – Public Employment Services/Statistics Sweden. Figures for each group are not mutually exclusive – Labour Force there all adults.

[3] Statistics Sweden surveys on living conditions of persons with disabilities (using ULF/SILC data set) aged 16 and older.

[4] Department of Trade and Pensions – all disabilities children and adults. England only; http://www.scotland.gov.uk/Topics/People/Equality/disability; http://www.scotland.gov.uk/Topics/People/Equality/disability;

[5] Emerson *et al* . People with Learning Disabilities in England – report of Learning Disability Public Health Observatory.

[6] The Czech Statistical Office (2007).

[7] Statistical Office of Republic of Serbia (2011 census).

[8] Central Statistics Office, Ireland (2011)

[9] Intellectual Disability database (2011)

[10] Physical and Sensory Disability Database (2011)

[11] Statistisches Bundesamt, (2011)

[12] ISTAT. Indagine sulla condizione di salute ed il ricorso ai servizi sanitari (2004-2005) see web site www.disabilitàin cifre.ir e www.istst.it.

Deinstitutionalisation

Definition, existence and nature of institutions

This section presents the data obtained from official statistical resources and, in some cases, other quantitative data sources from each of the countries involved in the study with regard to residential institutions. The Deinstitutionalisation and Community Living Outcomes and Costs (DECLOC) study (Mansell *et al*., 2007)[13] was also used to present information relevant to the theme. In the DECLOC study a residential institution was defined as an establishment in which more than 30 people lived, of whom at least 80% were mentally or physically disabled. However there has been trend in last two decades to define institutions by other indicators than primarily their size. Mansell, Beadle-Brown, *et al* (2010) note that institutions were originally defined in general as large congregate settings that function on a medical model and institutional practices as marked by social distance, rigidity of routine, block treatment, depersonalisation (King, Raynes and Tizard, 1971). Mansell, Beadle-Brown et al identified the common characteristics of institutions as: 1/ they were large establishments serving tens, hundreds or even thousands of people, 2/ they were physically and socially segregated from the wider society, 3/ whether by policy or for want of alternative sources of support, residents were not easily able to leave them to live elsewhere, 4/ material conditions of life were worse than for most people in the wider society. These authors also argue that it is possible to have institutional practices in small community based settings. Similarly People First of Canada describes institutions as follows: "An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place where people do not have, or are not allowed to exercise, control over their lives and their day-to-day decisions. An institution is not defined merely by its size."[14]

Table 2 shows that institutions exist in most of the countries involved in the study. In some countries data is collected about number of places available in residential services but not about number of people actually occupying them. It should also to be remembered that however services are named and classified in terms of desired nature of service in reality these names might not correspond with actual quality of services provided. For example, in the Czech Republic large residential provisions were officially named institutions up to 2006. Due to legislative changes the same settings are now named 'homes for people with disabilities'. However whether the people using those services now find these places to be 'homes' has not been explored and would require in-depth investigation. This is similar to what has been also observed in Denmark and in Finland where deinstitutionalisation took place through reclassification of the services rather than the services actually changing (Tøssebro et al, 2012)[15]. In countries such as in Serbia, Czech Republic and Germany, the number of residents living in institutions is relatively high. Similarly Italy has more than 190 000 people reported living in institutions. Overall, in all countries larger residential provisions are often for people with intellectual disability or mental health problems, less for people with physical or sensory impairments. There is a trend towards deinstitutionalisation primarily in social care sector in all the countries. In contrast institutional care in the mental health sector seems to be more reluctant to change to community based services in many countries.

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

[14] The National Community Inclusion Initiative. http://communityinclusion.ca/sectors/deinstitutionalization/

[15] Tøssebro et al. (2012) Normalization Fifty Years Beyond, *Journal of Policy and Practice in Intellectual Disabilities*, 9, 134-166, p. 136.

Table 2 Number of people in institutions

	Estimates from DECLOC (2007) >30 places	**Updated information**	**Which groups?**
Norway	N/A	150-200	People with severe physical or multiple disabilities (after accidents/stroke etc) living in Health and Welfare Centres
Sweden	0	Not provided	People with mental health problems live in their own apartments (supported by home help services or supported housing) or in group homes if they require more extensive support. Such group homes, with up to 20 persons, gradually close down and new group homes for 4-6 p persons are built.
UK	66,342	No updated figures available in general. However likely to be lower now as most of long stay institutions for people with ID are now closed (just a small number of places remaining in Northern Ireland and Scotland). NHS campuses in England are also now closed as are some of the NHS assessment and treatment units and private hospitals following Winterbourne view scandal. However 2601 people with intellectual disability or autism and mental health issues/challenging behaviour are still in assessment and treatment units or private hospitals[16].	Larger residential services, campuses, village communities tend to be for people with intellectual disabilities. Those with challenging/forensic behaviour are more likely to be in private hospitals or as a long term resident in assessment and treatment units. 1046 people with IDD reported to be in acute or long stay residential facilities/hospitals (2011). Some larger services also exist for those with physical or sensory impairments but this tends to be those with the most severe disabilities and they may also have an intellectual disability too. Some people with physical disabilities are in rehabilitative hospitals. Hospital accommodation is most common for those with severe mental health needs, or in some cases extreme health issues accompanying disabilities.
Czech Rep	30,987	None available	

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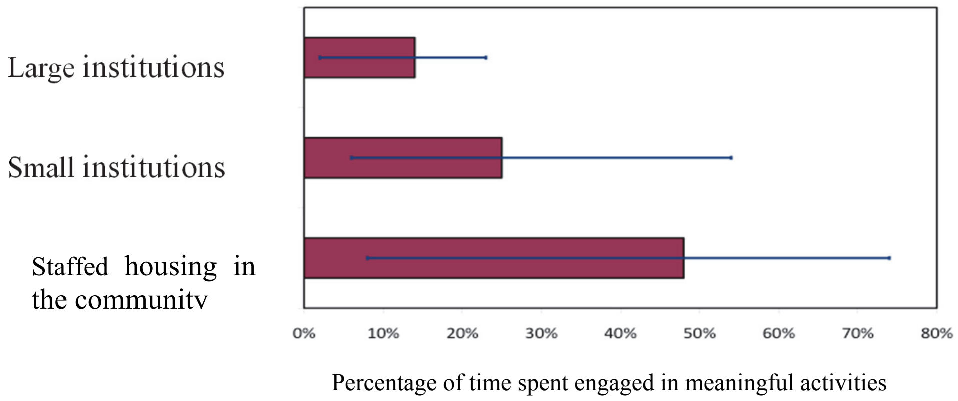
[16] http://www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/

	Estimates from DECLOC (2007) >30 places	Updated information	Which groups?
Serbia	N/A	Approx. 8000	Most groups – Proportions of those in institutions who have: physical disabilities (5,1%), sensory impairment (1,3%), intellectual disabilities (31,8%), psycho-social disabilities (46.7%), multiple disabilities (11.8%), pervasive developmental disorder (usually related to autism) (0.5%), other disabilities (2.9%).
Ireland	5,123	Approx. 4,000 (with IDD)	Mainly IDD in larger services but also some physical and sensory disabilities and some with mental health needs.
Germany	190,146	202,359	64% cognitive disabilities 26.2% psycho-social disabilities 9.3% Physical
Switzerland	N/A	Not available	NB. 25000 living in some type of service (but size not available). Breakdown by disability group in all settings: physical disability - 11.0%, mental disability - 20.1%, intellectual disability - 55.4% sensory disability - 2.7%, others (addiction etc.) - total - 10.7%
Italy	153,798	190,134	All groups.

Impact of deinstitutionalisation

There have been a number of substantial and systematic reviews about the impact of deinstitutionalisation, in particular around people with intellectual disability. These have focused primarily on research in the UK, USA and Australia although the most recent reviews did include studies in other countries too (Beadle-Brown *et al*., 2007; Kozma *et al*., 2009; Mansell and Beadle-Brown, 2009). The first review of the impact of deinstitutionalisation was conducted on studies completed in the UK and looked at a number of outcomes including a measure of engagement in meaningful activities and relationships – this is important because engagement is the route by which people achieve many aspects of active citizenship. Emerson and Hatton (1994) found that on average people living in smaller staffed homes in the community spent more time engaged in meaningful activities than those in small institutions and those in larger institutions (see Figure 1). However there was also substantial variability so that some people in community based settings experienced worse outcomes than some of those in institutions. However no one in institutions experienced as good outcomes as the best outcomes achieved in community based settings. This indicates that although moving people into the community is important to improving their quality of life, it is not sufficient and it led researchers to go on and explore the need for staff to have particular skills to enable people to make the most of the opportunities available to them.

Figure 1 Summary of findings from review of studies on deinstitutionalisation by Emerson and Hatton (1994) – mean and range of time spent engaged in meaningful activity



In the US Kim, Larson and Lakin (2001) reviewed US DI studies and found that in general outcomes in terms of adaptive behaviour were substantially better in community-based services. Only in a very small number of studies reviewed did outcome deteriorate for people. In terms of challenging behaviour for the most part there was no change in challenging behaviour although in a small number of studies this did increase (see Figure 2 below). Figures 3 and 4 show the findings from two other reviews which focused on a wider range of outcomes – Figure 3 summarises the findings from the review of Australian Deinstitutionalisation studies (Young *et al*., 1998).

Beadle-Brown *et al*. (2007) reviewed the literature on deinstitutionalisation during 2006 and found that research continued to show that outcomes are better in the community than in institutional care but recent papers highlighted that there is more to deinstitutionalization than just hospital closure. Just moving people out of institutions into community settings did not bring about automatic improvement in quality of life. This was true of choice and inclusion as well as self-identity and access to effective healthcare and treatment and was especially true for people with more severe intellectual disabilities and those with complex needs such as challenging behaviour. Some of the research reviewed illustrated that even offenders with intellectual disability could be successfully supported in the community.

Figure 4 presents the findings of the most recent and most international review (Kozma *et al*., 2009). As can be seen, the overall picture is for better outcomes across a whole range of outcomes after moving to the community. Outcomes were particularly favourable with regards to self-determination and autonomy, social relationships and friendships and community presence and participation. Finally, Mansell and Beadle-Brown (2009) found that dispersed housing was equal to or, for the most part, better than clustered or congregated settings on all quality of life domains. The only type of clustered setting that had some advantages for people with mild levels of intellectual disability were village or intentional communities. However the authors concluded that this was not a model with widespread feasibility and there was no evidence that such congregate or clustered setting could provide as good outcomes as good dispersed community based settings.

With regard to people with mental health conditions findings of the impact of deinstitutionalisation were also primarily positive although research is harder to find (see for example Hempel 2009[17]; Thornicroft *et al*., 2005[18]).

Within the nine countries featured in the current report evidence of impact of deinstitutionalisation on the lives of the people who moved was available for 4 of the countries from research although some other reflections of the authors of templates are also included.

In Norway, research on deinstitutionalisation for people with intellectual disabilities is more easily identified than for any other groups partly because it took the process of change too the form of a structured government-led reform. The research from Norway (Tøssebro, 1996; Söderström and Tøssebro, 2011) suggested that the quality of living arrangements improved considerably in community-based services and that the improved material conditions also had social consequences: for example, it was reported that there were less conflicts between fellow residents and more contact with family because visiting felt more like a private visit in the community-based services. There was also increased self-determination in everyday affairs, but not regarding questions such as where to live and with whom. At the onset of the reform years, there were some neighbourhood protests but intellectually disabled people were quickly accepted in the neighbourhood and it is now a common thing to meet intellectually disabled people on the bus or in the store. It is not full integration or inclusion, but a substantial improvement on the situation before the institutions was closed. However, on life domains such as employment and social networks, the reform did not bring about many changes.

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[17] Hempel, V. (2009) The Impact of Deinstitutionalisation: Where to From Here? , *Social & Public Policy Review*, 3, 1, pp. 17-33.

[18] Thornicroft, Bebbington and Leff (2005) Outcomes for Long-Term Patients One Year After Discharge From a Psychiatric Hospital, Ph.D. PSYCHIATRIC SERVICES http://ps.psychiatryonline.org, November 2005 Vol. 56 No. 11

Many parents feared the reform before it started but a vast majority changed their mind after resettlement, and three out of four saw it as an improvement whereas only 17% found institutions better (Tøssebro & Lundeby, 2006). Ninety percent found the new housing arrangements better and none worse.

In Sweden there was some evidence that those who have experience of being in mental asylums strongly prefer living in the community even though this means being poorly integrated in social networks and feeling lonely. However, persons with mental health problems still experience a number of difficulties: social isolation, poor networks (most social contacts take place with care and social support professionals, poor financial circumstances, lack of employment, difficulty to navigating in the welfare landscape and find relevant support, poor housing etc. Compared to life in the institutional era, living conditions seem to be better despite above mentioned difficulties.[19]

The research from the UK featured in the reviews already mentioned above with regards to people with intellectual and developmental disabilities. The paper by Thornicroft *et al*. (2005) found that there had been significant improvements in social networks of people with mental health conditions. They also found that patients expressed a preference for community settings, and the quality of the clinical environment was also noted.

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[19] SOU 2006:100 *Ambition och ansvar*. Slutbetänkande från Nationell psykiatrisamordning (Ambition and Responsibility. Final report by the National Psychiatry Coordinator) pp. 113-114.

Figure 2 Summary of papers on deinstitutionalisaiton in US reviewed by Kim *et al.* (2001)

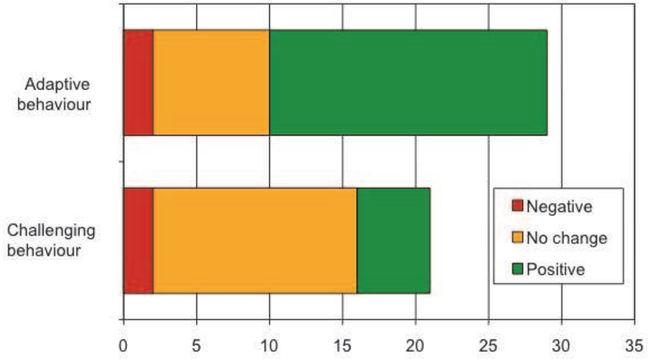


Figure 3 Young *et al (1998)*- summary of Deinstitutionalisation studies in Australia.

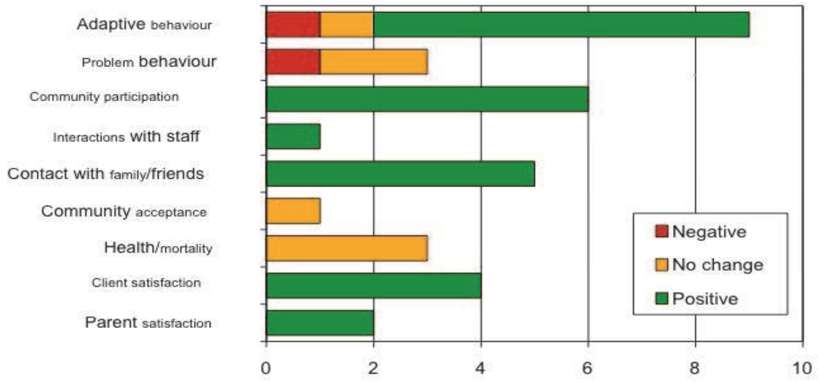
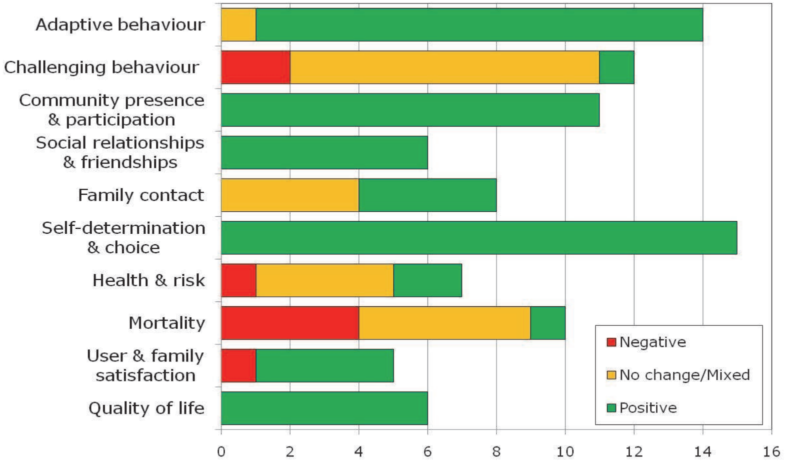


Figure 4 Summary of studies reviewed by Kozma *et al.* (2009)



In Switzerland, Gehrig et al. (2013) reported that the percentage of people in institutions who reported themselves as somewhat or very dissatisfied with their living arrangements (4.2%) was similar to the those living at home (7.3%). However fewer of those living in institutions indicated that they were *very* satisfied (29.4%) compared to those living at home (53.1%) (Gehrig et al. 2013: 17).

In the Czech Republic and Serbia deinstitutionalisation has only recently started. Therefore there is almost no evidence about the progress. Nevertheless Šiška & Káňová (2013)[20] analysed 32 institutions participating in a deinstitutionalisation programme funded by the EU between 2010 and 2013. The results of the analysis indicated that providers are moving towards smaller residential arrangements or community based support. However these conclusions should to be taken with caution due to the limitations with the data and the variation in type of service that people are moved into as a "community-based" service. For example, although privacy was found in general to be greater in the community based services, some people were found to still be living in shared bedrooms with 3 other people and some where even sharing rooms with 6 other people. Nevertheless a trend towards community participation in the Czech Republic is evident in, for example, employment of the residents from these institutions. The service providers involved in the study reported an increasing trend towards employment of people with disabilities outside of their residential facilities.

Finally, in Germany, research in 2010 (Metzler & Springer, 2010: 48) accompanied a decentralisation / deinstitutionalisation project of 10 members of the catholic social association 'Caritas'. The aim of the deinstitutionalisation project was to convert 1,482 places formerly situated in 'Groß- und Komplexeinrichtungen' (big residential homes or institutions) to community-based, more decentralised homes. Seven hundred and seventy-two persons with disabilities were involved. They found that privacy improved for people; while only 36% reported to have had privacy in their former residential accommodation, 82% reported improvement in privacy after the relocation. With regard to self-determination, 64% of people reported that their opportunities for self-determination, and therefore choice and control over their lives, increased after the relocation (page 69). The increased in self-determination included: more flexible meal times; less obligatory activities; having their own keys for the apartment, their own telephone, their own bank account etc. Most of the people who moved out of residential care considered rated their new community based home as better than where they had lived before the move (Metzler & Springer, 2010: 82).

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[20] Šiška, J., Káňová, Š. (2013) *Kvantitativní* analýza deinstitucionalizace sociálních služeb v České republice. *Sociální práce / Sociálná práca.* No. 2, pgs. 117 – 129.

Evidence of re-institutionalisation and barriers to DI

Table 3 Re-institutionalisation and barriers to deinstitutionalisation

	Issues of re-institutionalisation or stagnation of /barriers to the process of deinstitutionalisation
Norway	Norway closed all institutions for people with intellectual disability from 1991-96, setting up group homes with 3-5 residents or fewer. However recently there has been a rather dramatic change in size and composition of group homes. The mean size of group homes has moved from 4 to 7, and the mean among newer group homes is eight. This would have been illegal in the 1990s. Many new group homes are for more people than most institutions built in the 1980s (few institutions built in the 1980s were for more than 10 people). In addition to this we see that the number without daytime activity has increased threefold from 1995 to 2010, from 5 to 16%. In some cases these are people with mild intellectual disabilities, but for people with more severe disabilities it also means that services become more total in character. Newer slightly larger group homes are also less integrated into a typical neighbourhood, creating an image of “home of deviant people” rather than a normal house. Also a change in daytime occupation – fewer people in supported and sheltered employment, fewer in work-type activity centres; more people without daytime activity or in centres mainly providing leisure activities. People experiencing less self-determination in everyday matters. [21] Also number of people with severe disabilities following an accident or stroke, illness etc. in nursing homes for elderly people is not declining. People with early onset dementia also likely to go into elderly nursing homes. The main reason for these changes appears to be the governance structure. Autonomous local governments are responsible for services and they do not appear to feel obliged to follow national guidelines. More strict national regulations might be needed.
Sweden	The LSS-reform in 1994 strongly emphasized that institutions for physical and intellectually disabled ought to be closed down. Responsibility for social care, occupational and leisure activities were also transferred from the regional county health authorities to the local municipalities. A psychiatric health care reform in 1995 took the same position re persons with psychiatric disabilities. However, reform intentions and local practices often differ. More recently, special homes for disabled people often co-located with other special residences or the elderly and people with mental health problems so that staff can be shared especially at night. Sheltered apartments (with specific services) are also linked to group homes so that common areas in the group homes are used by people in nearby sheltered apartments. Although community based disability services are established in law as a right, it is not always implemented in practice due to e.g. difficulty recruiting personal assistants and contact people to match the needs and wishes of the user. Staff turnover is high. Some local authorities also find it difficult to provide residential and respite services. Even the requirement to immediately provide special residence if needed by an individual, is not always executed as the individual has to wait for the municipality to find or organise a suitable residence.
UK	Average size of care home has been increasing between 2004 and 2008 – most recent figures were 9.6 places (2007-2008). Biggest increase for services for older adults. For people with ID, home size is still smallest. The current inspection and registration body (CQC) do not report size of home data in their annual report. Private sector services tend to be bigger and of poorer quality than voluntary sector services. Services originally set up as private specialist hospitals or assessment and treatment units are generally bigger and although people are

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[21] Tøssebro *et al* ., (2012) Journal of Policy and Practice in Intellectual Disability

	only supposed to be there for a short period of time – there is evidence that a small number of people with ID stay in acute services there for 10-12 years. These are usually for people with challenging behaviour or forensic needs. In the UK there is no law that limits the size of residential or other services - registration is on the basis of the person setting the home being seen as a fit person to manage such a service. As such services for 30 or 40 people can still be set up although these are usually by private organisations. Recent scandals have drawn attention to the failings of some of these services and it the process for inspection and registration is currently changing. However current financial crisis has meant a reduction in budgets for local authorities which have been transferred to service providers and to personal budgets in many cases.
Czech Republic	Process of deinstitutionalisation only just started and not yet in all regions. Those with more severe disabilities less likely to move out of institutions in this early stage. No evidence of re-institutionalisation yet.
Serbia	Deinstitutionalisation only just starting. No evidence yet that EU funds would financially support institutional care however World Bank financially supports one energy efficiency project at one institution. Only in one institution, where one new pavilion has been built, has there been any investment. There are projects allowing institutions to build sheltered living not within the institution. This new type of service is, however, run by the same staff with a big risk of replicating institutional culture. New Social Welfare Law suggests a wide range of new services that should encourage and enable life within the community; the services are not institutionalised but are not available yet. Competences for developing such services were transferred to the local level. Children and adults are still placed in institutions according to their diagnosis regardless of their place of residence. This represents another form of discrimination and makes maintaining contact with family relatives and return to the natural surroundings much more difficult. Supported living is mainly available for clients with less severe disabilities and already very independent who need very low levels of support.
Ireland	State funds currently still support people in larger residential and institutional services but the process of wide-spread deinstitutionalisation for people with intellectual disabilities is currently at an early stage (although some excellent examples of community based services already exist). “Time to Move on from Congregated Settings” commented in its review of the 619 individuals who had moved from congregated settings in the period 1999-2008, ‘Many of the residential services have, over the years developed some community-based, as well as campus-based, provisions. Younger residential service users are more likely to live in the community-based services whereas older service users are more likely to live in campus settings. In some cases, individuals who were ‘more able’ were moved to a more community-based service. Therefore, many people were left behind and those whose needs are more complex in a variety of ways’. (p.53). Poverty of individuals, the high cost of private/independent sector services and cuts in service funding from government has result in people with disabilities being forced to move back into institutional care. State financed residential care services are being used rather then independent living due to cuts in the budget. Lack of community support for senior citizens force them to move into nursing homes.

Germany	Germany was one of the countries found by Townsley *et al* (2010)[22] to have shown new or increased levels of expenditure on institutional care, the building or development of new institutions. Those who needed 24 hour support find it increasingly difficult to get enough support outside of institutions – usually due to financial reasons – i.e. where community based support would be 'disproportionally" more expensive than institutional support. However Waldschmidt (2009) comments that these decisions are not regulated and are taken by the responsible administration. Although people have the right to choose different types of support, there have been cases where people have been forced to live in institutions – especially where people have severe disabilities and need 24 hour support. Authorities tend to fund the lower cost option[23].
Switzerland	1) People in need of extensive support are often pushed towards moving into a residential facility for financial reasons, instead of being enabled to live the life that they would like to live, namely, in their own apartment with assistance. In this way, these individuals do not have a free choice of their place of residence as CRPD Art. 19 stipulate. 2) Agencies misuse the Personal Budget scheme frequently in order to save expenses. In contrast to the legal stipulations, it thus becomes necessary to fight for individual benefits and services in budget conferences, 3) the procedures for the determination of an individual´s needs and requirements (which) are complicated, and strongly characterized by the pressure to make financial cutbacks (information based on the CRPD shadow report
Italy	Following the cuts in social service funds there is a growing number of residential institutions as well as an increased number of older people being institutionalised. However at the same time the number of families placing their members with disabilities in institutions decreased. 70.1% of those with severe disabilities cannot access assistance for living in normal housing.

It is evident from the national reports that the countries studied appear to be at different stages of deinstitutionalisation. In some countries such as Norway, Sweden and the UK the closure of the old style institutions is completed. In Serbia and the Czech Republic deinstitutionalisation has only recently started. In some countries such as Italy the process is more advance for those with mental health conditions than those with intellectual disabilities, while in Germany for example, those with the less severe disabilities have the opportunity to live in the community. Nevertheless, the overall picture is not very encouraging. It can be seen in Table 3 that some countries appear to be either re-institutionalising people with disabilities or to be stagnant in the process. For example, in Norway services for intellectually disabled people run by autonomous local governments are changing in a direction that is opposite to the national policy guidelines and getting larger – newer group homes are being built at sizes that would not have been permitted in 1992. More services are being established as 'total services' – i.e. providing for all people's needs onsite so that use of community based

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[22] Townsley, R., Ward, L., Abbott, D., & Williams, V. (2010). *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report. Report for ANED - Academic Network of European Disability experts.* Retrieved 23.10.2013, from http://www.disability-europe.net/content/aned/media/ANED-Task%205%20Independent%20Living%20Synthesis%20Report%2014.01.10.pdf.

[23] Waldschmidt, A. (2009). *ANED country report on the implementation of policies supporting independent living for disabled people - Germany. Report for ANED - Academic Network of European Disability experts.* . Retrieved 22.10.2013, from http://www.disability-europe.net/content/aned/media/DE-8-ANED%202009%20Task%205%20Request-07%20Independent%20living%2009-06-26_to%20publish%2017-08-09_to%20EC.pdf

services and facilities is limited. A Swedish monitoring report by County Administrative Boards in 2007 found that 9 out of 10 municipalities were using guidelines that conflicted with the law. Group homes in Sweden were starting to be co-located with other services such as homes for older adults or mental health services and staff shared across the settings. In the UK, the average size of care home is increasing and it is still possible for an individual or organisation to set up a service for 20, 30 or even 40 people with intellectual disabilities. Larger residential services, with as many as 20 people, are also still found in the UK. So, even in Norway and Sweden where the citizen perspective is the strongest with rights clearly set out in the law, there is a gap between policy and ideology and practice. Staff turnover and shortage of staff was reported as a barrier to deinstitutionalisation as well as a reason for services getting bigger or being clustered together. A lack of adequate community mental health support was raised as an issue for those with mental health problems. In the UK cost is seen as a constant constraint – services are provided only to those with the most severe needs – those whose lives would be in danger without such services.

However cost is also an issue in other countries - cuts in public spending in Italy are reported to have led to an increase in the number of institutions and in particular the number of older people in institutions. However there is also a trend for younger families to refuse to put their son or daughter in institutional care.

In Ireland poverty is an issue for people who are even partly funding their own support in the community, forcing some people to return to larger congregate settings. Ireland has also been fighting a movement from organisations to move to clustered settings rather than dispersed homes in the community.

In Serbia children and adults are still placed in institutions according to their diagnosis regardless of their place of residence – sometimes a long way away from their own community. This represents another form of discrimination and makes maintaining contact with family relatives and return to the natural community much more difficult. Again, policy is now encouraging the shift to community based services for all but implementation is slow. Only those with the least severe disabilities get to live in their own home with a small level of support.

Similarly in Germany, Ireland and Switzerland, supported living (where people receive support in their own home) or other forms of community based support is mainly available for clients with less severe disabilities. In Germany people with severe intellectual or physical disabilities are often forced to live in institutions as they would not be provided with enough staff support in the community to meet their needs.

Community based services for people with disabilities

Supporting disabled people to live in the community as equal citizens is an issue of human rights. As reviewed above, a number of reviews of the research has found that community based services show better results for people receiving them[24]. However as mentioned above, moving to community based services is not a guarantee of better outcomes. Community based services often refers to the approach to support which entails the separation of support from provision of accommodation (sometimes called Supported Living as opposed to Residential Care). The support is provided to them within their own home or in a way which facilitates access to employment, education, leisure or other activities in the community. People are involved in planning their support, such as where they live and who supports them. Overall these services are intended to support people to live as full citizens rather than expecting people to fit into standardised models or structures. However, as with the situation regarding deinstitutionalisation, there is often a gap between the ideology and reality – as noted above the quality of support even in such small, individualised services can vary and in some cases the practices of staff create the institution in the community. As Mansell and Beadle-Brown (2012) note, what makes a difference to the experience of people with disabilities is how staff support people to make the most of the opportunities available to them in the community, whether they live in their own home or whether they live in a small group home or an apartment rented for them by an NGO. It is not possible to effectively provide this type of person-centred support in large congregate settings.

Table 4 shows where people with disabilities live in each country and numbers/proportions where available. This section also presents policies and systems which promote community based services. It should be remembered that in most countries involved in the study, the institutional and medical model has played a major role in service policies. Therefore data referring to community based services are often incomplete.

Nature of community based services

Table 4 presents data on the number of people with disabilities living with families, number of people living in small group homes (<10 places), in apartments with support, in own homes with assistance and in larger residential homes (more than 10 but less 30). In the countries studies where such information is available (mainly on Intellectual Disabilities), the numbers significantly vary. For example in Norway in 1999 21 % of people with intellectual disability lived with families, in UK in 2004 it was approximately 60 % and Ireland 66.4 %. In Norway, Sweden, UK and Switzerland most people live either with families or in smaller group homes. In Germany and Czech Republic smaller residential provisions exit but exact numbers are not available. The breakdown by type of disability is not known except for Ireland. However, group homes either small or large seem to be mainly occupied by people with intellectual disabilities and, in the UK and Ireland, also by people with physical and sensory disabilities.

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[24] e.g. Emerson and Hatton, (1994); Young *et al*. (1998); Kim *et al*. (2001); Kozma *et al*. (2009)

Table 4 Where people with disabilities live in each country and numbers/proportions where available.

	Living with family	**Small groups homes (<10 places) – usually 24Hr support**	**Apartment with support provided by/funded by state etc. – usually less than 24 hour support**	**Own home (rented/owned) with assistance (up to 24 hrs)**	**Larger residential home (10 or more but less than 30 - ? community based service).**
Norway	98% of children live with family. No exact figures available for adults provided. In 1999 21% of people with ID over 21 lived with their families.	Yes – primarily for people with ID – average size 7 places.	Yes both for people with ID and some for people with MH	Yes – 15% of people with ID are in this type of setting	Lately some group homes for more than 10 people are set up but very few above 30. In the 1990s few group homes were for more than 5.
Sweden	Not available.	Yes – for all client groups	Not clear from the data.	Yes	
UK	No official figures but various reports have found that around 60% of adults with ID live with family. 2004 Learning Disability Survey found 67% in family home.	Yes – this still remains the most common form of accommodation and support service in the UK	Yes – exists usually for people with challenging behaviour	Yes – this is increasing. In 2010/2011 42,625 people with ID were using self-directed support or direct payments - 81% ore than 2009/2010. However the biggest increase was for council services only - i.e. where the individual allocation is still used to pay for social care services that are traditional and not really new models	Yes – there are some larger residential services based in the community that provide for between 10 and 30 people (usually less than 20). Primarily for people with ID but also with physical and sensory disabilities.
Czech Republic	Numbers not available	Yes – usually 6 to 10 places – all disability groups but not mixed.	Yes – some institutions rent flats for those who don't need so much support to live in – usually as a group though.	Is possible with social assistance funding. Tendency growing but no exact numbers available.	
Serbia	563000 live with families – 98% of those with a disability.	441 adults and 661 children (size not indicated)		196 adults	
Ireland	85.5% of people with physical and sensory disabilities and 66.4% of people with ID live with family members	4226 People with ID Also people with PD			2561 people with ID 343 people with physical and sensory dis. 52 people with mental health problems.

	Living with family	Small groups homes (<10 places) – usually 24Hr support	Apartment with support provided by/funded by state etc. – usually less than 24 hour support	Own home (rented/owned) with assistance (up to 24 hrs)	Larger residential home (10 or more but less than 30 - ? community based service).
Germany	No recent figures available – in 1990s had been estimated at approximately half of people with disabilities.	No recent figures but DECLOC report identified that this type of service exists, although in the minority.	No recent figures but DECLOC report identified that this type of service exists, although in the minority.	No recent figures but DECLOC report identified that this type of service exists, although in the minority.	No recent figures but DECLOC report identified that this type of service exists – most common type of community based support.
Switzerland	NB No data available for living with family – only private households which are not necessarily family homes – could be person in their own home.	1,134,000 persons with disabilities (94%) lived in private households in 2010: physical disability - 76.4% mental disability 6.8% both 15.8% neither physical nor mental 1.0% Personal assistance payments: persons with disabilities who are unable to take care of themselves are entitled to receive extra disability benefits to pay for the extra costs that arise due to these limitations. The percentage of persons who receive such benefits and who live at home has risen from 50% in 2004 to 59% in 2011. There were more than 25000 people living in some form of service provision (referred to as institutions but no information available on size) physical disability 11.0%, mental disability 20.1% intellectual disability 55.4% , sensory disability 2.7%, others (addiction etc.) 10.7%			
Italy	Majority live with their family – main support for 83% of people with disabilities is their family.	Smaller family houses form 7 to 9 places	Supported Apartments – from 1 to 4 people who have chosen to live with other people. Only for people with physical and sensory impairments with low support needs.		Smaller Sanitarium Residences – RSA – from 12 to 120 people. 2 or more people frequently share a room. Larger family Houses – from 10 – 20 places

Policies to support DI and the development of community based support

As many authors have stated, it is not that difficult to close institutions but much harder to replace these with a coordinated collection of community based arrangements that offer the support and opportunity needed and wanted by disabled people. National policy frameworks are regarded as key ingredients for a successful widespread replacement of institutions (Mansell J, Knapp M, Beadle-Brown J and Beecham, J, 2007). All countries studied reported policies to support deinstitutionalisation and community based services. Among countries reporting policies based explicitly on UN CRPD, Germany has the National Action Plan on the Implementation of the UN CRPD which describes the foreseen provisions for implementing the CRPD although, with regard to community living there are few concrete provisions described on how to foster community based living arrangements. In the Czech Republic the Plan on Creating Equal Opportunities for People with Disabilities 2010 – 2014 is structured according the CRPD articles. Regarding article 19, the Plan calls for sustainability of reform of social services. Similarly in Serbia the Strategy for Improvement of Position of Persons with Disabilities 2007–2015 requires implementation of deinstitutionalisation. In addition, each Serbian institution has a duty to develop and implement a transformation plan. The UK adopts policies related to community-based support almost on a yearly basis. The most up-to-date strategic document "Fulfilling Potential" (2013) summarises policy and highlights the need to support disabled people to live independent lives, to personalise services, to give more choice and control and to improve opportunities to work and to play a full part in society. "Valuing People Now" (2009) highlighted the need to implement existing policy with respect to people with learning disabilities including those with the most severe needs. Ireland has built up its policy recommendations on the basis of research, reviews and reports. In Ireland "Time to Move on from Congregated Settings - A Strategy for Community Inclusion 2011" explicitly called for moving from congregative settings (10 residents or more), while "New Directions – Review of HSE Day Services and Implementation Plan 2012 – 2016" set up as a guiding principle that support should be tailored to individual need, flexible and person-centred. In general, all countries studied have enacted laws which undertake providers of social services and other relevant stakeholders to follow principles of self-determination of service users and their social inclusion. Sweden and Norway have gone even further. In these countries it is not permitted to build institutions for people with disabilities.

Table 5 Examples of legislation, policy, strategies that support deinstitutionalisation and the development of community based support.

	Examples of Legislation/other policy/government strategies that supports development of community based support
Norway	Husbankens låneordninger [The National Housing Bank] - Funding of local government building of group homes and "care homes" (apartments for people with service needs) Avviklingsloven [The act of dissolution of institutions for intellectually disabled people] - A law that made institutions for intellectually disabled people illegal and a plan for resettlement from 1991-1996 Helse- og omsorgsloven [Law on local health and social services] - Places the responsibility for a number of community care services on local governments Opptrappingsplanen for psykisk helse [Expansion plan for people with mental health difficulties] - Plan for more resources and more community based services for people with mental health difficulties Økonomiske overføringer fra stat til kommune [Economic transfers from national to local government] - A system for economic support from the state to local government. Local governments receive a standard lump sum of money for each individual with for instance intellectual disabilities. Not earmarked. Social security: The means of livelihood of severely disabled people living in the community is typically the incapacity benefit (about 2000 euro a month).
Sweden	Health Care Act - Disabled persons have access to hospital care, primary health care, and rehabilitation services on same terms as others. Social Services Act - Disabled persons have access to cash allowances and services in order obtain a "reasonable" level of living. In addition needs-tested special services like adapted housing, supported housing, daily activities, contact person etc may be provided. Social Security Act - Within the framework of the social security system, people with disabilities (aged 16-64) or parents of children with disabilities can apply for disability allowance, i.e.,to cash benefits for the purpose of managing additional living costs due to disability. Benefits are calculated according to the amount of help needed or the magnitude of such additional costs.[25] Parents having a disabled child may be entitled to care benefits (*vårdbidrag*) to manage additional living and caring costs. Parents having a disabled child may also be entitled a longer period of paid and income-related parental leave compared to others. Financial support can also be provided to obtain motor vehicles (*bilstöd*).[26] The aim is that people with disabilities should be mobile to the same extent as any other person. Financial support is given in order to a) obtain a car, motorcycle or moped; b) change a vehicle; c) acquire special devices or facilities for the vehicle; and d) acquire a driving licence in connection with obtaining a vehicle. The maximum financial support for obtaining a vehicle is 40,000 SEK and it is only granted to people with a fairly low annual income. Benefits may be granted every seventh year. Special Support and Services (Law on Special support and Services for persons with disabilities, LSS 1993) – made provision for personal assistance and other forms of support within the home allowing people to live in their own home.
UK	Independent Living Strategy (2008) – a cross government strategy including employment, transport, health education and communities) – now superseded by: Caring for our future (2012) – radical reform with a 10 year implementation timetable. Two core principles – 1) the system should do everything possible to prevent, postpone and minimise people's need for formal care and support – based around idea of promoting people's independence and wellbeing. 2) People should be in control of their own care and support – based on idea of direct payments and personal budgets combined with clear, comparable information and advice to allow people to make informed choices. It includes improving the support for carers and the quality of care and support for

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[25] Lindqvist, R. (2010) *Funktionshindrade i välfärdssamhället*. (Disabled people in the welfare society) Gleerups: Malmö; Lindqvist, R. (2000) 'Swedish disability policy. From universal welfare to civil rights' in *European journal of social security*, 2 (4), pp. 399-418.

[26] Swedish Code of Statues (*Svensk författningssamling*, SFS) *1988:890* Regulation on vehicle allowance (*Förordning om bilstöd*).

	Examples of Legislation/other policy/government strategies that supports development of community based support
	individuals themselves. Fulfilling Potential (2013) – produced by the Department of Work and Pensions, summarises current policy in England and highlights major reforms to support disabled people to live independent lives, to personalise services, to give more choice and control and to improve opportunities to work and to play a full part in society. Valuing People Now (2009) – focused on improving personalisation and inclusion of people with learning disabilities including those with the most severe needs. Same as You (2000) - Ten year plan for improving the lives of people with ID in Scotland Fulfilling the Promises (2001) – plan for improving lives of people with ID in Wales.
Czech Republic	National Plan on Creating Equal Opportunities for People with Disabilities 2010-2014, Government Resolution No. 253 (February 1, 2007) - states that a gradually increasing number people with disabilities are being supported in their home environment and proposes to continue with those reforms in residential services and ensure the financial balance and stability of the social services system[27]. Conception of Support for Transformation of Social Services into other social services provided in community and supporting social inclusion of a service user into community. This strategic document determines objectives and measures to support the process of transformation and deinstitutionalization currently underway in the Czech Republic. The transformation process in the years 2009 – 2013 is supported in particular by the individual project of the Ministry of Labour and Social Affairs "Support of the Transformation of Social Services“ funded by the European Social Fund under the priority 4.3 Social Integration and Equal Opportunities of the Operational Programme Human Resources and Employment. In total, CZK 136,250,000 was allocated for this project. The general aim of the project is, based on detailed analyses and mapping the current situation regarding social services, to arrange for a comprehensive system to support the transformation of such services. [28]
Serbia	Law on Social Protection.[29] – This legislation both defines social services and provides a list of social services that people have access to. The Law also for the first time allows a range of non-governmental organisations and private persons/ companies to provide community based services. A positive aspect of the law is that it recognizes that quality of care and service is crucial in provision of the same. Therefore, each type of social service requires a defined set of standards and accreditation. The law also introduces procedures for accreditation of programs and education for service providers which are closely regulated by accompanying bylaw.[30] Strategy for Improvement of Position of Persons with Disabilities[31] - This Strategy defines a plan for implementation of the improvement in the position of persons with disabilities from 2007 to 2015.[32] Deinstitutionalization or transformation of institutional care is not included in general goals[33] under this strategy, but is mentioned in the Measure 4 of the

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[27] Available at www.vlada.cz/cz/ppov/vvzpo/dokumenty/narodni-plan-vytvareni-rovnych-prilezitosti-pro-osoby-se-zdravotnim-postizenim-na-obdobi-2010---2014-70026/ Government resolution No. 127 (February 1, 2007)

[28] Resolution of the Government of the Czech Republic of 21 February 2007 No. 127

[29] Official Gazette of the Republic of Serbia, No.24/2011, Law of Social Protection.

[30] Official Gazette of the Republic of Serbia, No. 24/11, Guidelines on licencing social care organizations

[31] Official Gazette of the Republic of Serbia, No. 1/2007, Strategy for Improvement of Position of Persons with Disabilities in Republic of Serbia.

[32] While several municipalities and towns have adopted local action plans for persons with disabilities, at the moment of writing, no national action plan has been adopted.

[33] Mainstreaming disability into general development plans, developing effective legal protection with implementation of prevention plans, developing policy measures and programs in areas of education, employment, work and housing, ensuring access to persons with disabilities to built environment, transportation, communication and public services.

	Examples of Legislation/other policy/government strategies that supports development of community based support
	Specific objective 5: To improve system of support and services directed to users in accordance to their needs which explicitly refers to deinstitutionalization stating that social, health and other services for persons with disabilities must fully respect principle of accessibility of services in local community "with full implementation of the process of deinstitutionalization." Similar wording is repeated in the Measure 1 of the *Specific objective 6: to strengthen families of persons with disabilities through system of providing adequate support of appropriate services which help integration of persons with disabilities in the community*. At the same time, the process of deinstitutionalization is nowhere yet defined in the state documents, nor are any steps or deadlines foreseen. The Strategy for Development of Social Protection[34] - provides the most detailed account on future plans on deinstitutionalization and defines the direction of the reform in residential services for children and adults with disabilities. It states specifically that children should be supported through fostering and adoption while service for adults should be focused on family placement and smaller capacity placements as close to the natural surroundings of the user as possible. It also sets out the need for an increase of type, quantity and quality of services. The strategy requires transformation plans for each institution. Rule book on the conditions and standards for the provision of social welfare services[35] - this defines conditions and standards that have to be followed by all service providers – these are common structural and functional standards for all types of social services, including residential services. Part IV defines conditions and standards for daily community based services. Part V defines support services for independent living.
Ireland	New Directions – Review of HSE Day Services and Implementation Plan 2012 – 2016 and Working Group Report – February 2012 [36] **-** This report reviews the provision of adult personal support or day services provided by the Health Service Executive in Ireland. It sets out that all supports that are based in the community will be mobilized in order to give the users the most choices in how they live their lives and spend their time. The guiding principle is that supports will be tailored to individual need and will be flexible, responsive and person-centred Value for Money and Policy Review of Disability Services in Ireland [37] **-** This Review is an evaluation of the efficiency and effectiveness of the HSE-funded statutory and non-statutory disability services in Ireland. One of its objectives for delivering services in the future is to provide support for people to live independently. They also envisage the provision of supports to enable individuals to live in the community and be fully included in community life. Time to Move on from Congregated Settings - A Strategy for Community Inclusion [38] - The report is a key step in establishing a national plan to move form congregated settings, in which 10 people or more live, to community living. It recommends that the 4000 people then living in institutional settings are moved to the community to either live alone, with a/their family or with other people with disabilities. A Vision for Change - Report of the Expert Group on Mental Health Policy[39] - The report sets out that each citizen should have access to local, specialised and comprehensive mental health service provision that is of the highest standard.

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[34] Official Gazette of the Republic of Serbia, No. 108/2005, 71/05, Strategy for Development of Social Protection.

[35] Official Gazette of the Republic of Serbia, No.24/11, Rule book on the conditions and standards for the provision of social welfare services

[36] http://www.hse.ie/eng/services/Publications/services/Disability/newdirections2012.pdf

[37] Department of Health – 2012 http://www.dohc.ie/publications/VFM_Disability_Services_Programme_2012.html

[38] Health Service Executive – June 2011 http://www.hse.ie/eng/services/Publications/services/Disability/timetomoveon.pdf

[39] Department of Health – 2006 http://www.dohc.ie/publications/pdf/vision_for_change.pdf?direct=1

	Examples of Legislation/other policy/government strategies that supports development of community based support
Germany	Social Code Book XII, section 13 - Officially community based assistance and care has a priority in comparison to residential care, "but this priority is not valid if its execution would result in disproportionately extra costs in comparison with institutional support. However, the term 'disproportionately extra costs' is not regulated and exact sums are not numbered; the decision is taken by the responsible administration which considers the individual case in question and the social budget of the respective region. Officially disabled people have the right to opt for different types of institutional and home care." (Waldschmidt, 2009: 8) "Unser Weg in eine inklusive Gesellschaft" Nationaler Aktionsplan der Bundesregierung zur Umsetzung der UN-Konvention (National Action Plan on the implementation of the CRPD): Barrier-free buildings: according to the BGG (see Annex) the German Federation is obliged to build in a barrier-free way and corresponding to the DIN (Deutsches Institut für Normung)-standards (German institute for standardisation). Requirements of persons with cognitive impairments are less considered (Bundesministerium für Arbeit und Soziales, 2011: 70-71) Living: when new buildings with several apartments are built, barrier-free apartments have to be included. Barrier-free (re)building is being supported financially (Bundesministerium für Arbeit und Soziales, 2011: 71-72) Inclusive social environment: the personal budget is regarded as a central instrument for the self-determined participation and was introduced in 2008. Furthermore the community based support net and social services are part of the programme "Soziales Wohnen im Alter" (Social living in old age). (Bundesministerium für Arbeit und Soziales, 2011: 72-73)
Switzerland	Hilflosenentschädigung, Assistenzbeitrag [helplessness and personal assistance payment] - Persons with disabilities who are unable to take care of themselves are entitled to receive extra disability benefits to pay for the extra cost that arise due to these limitations. These benefits were introduced with the express aim to improve the participation of persons with disabilities and to allow more people to live independently instead of in an institution. According to a survey commissioned by the Federal Social Insurance Office, the percentage of persons who receive such benefits and who live at home has risen from 50% in 2004 to 59% in 2011. More than 70% of the persons surveyed indicated that without these benefits they would not be able to afford living at home. [40]
Italy	Law 328/2000 - prohibits the institutionalization of minors and the Law 180/78 - abolished the psychiatric hospitals Law 104/92) - Domestic assistance (art. 9) - A limited number of hours per week are provided (from 1 h to 10 hour per week depending on local authorities) Law 162/98 - Independent living project (but only some regions offer this service) – The service covers only 6/20 regions. The most virtuous Region is Sardegna, which provides about 31.000 individualized projects with a budget directly managed by the beneficiaries. Law 13/89 - Removal of architectural and sensorial barriers in private houses - The national law are not yet financed, so only some regions cover this need.

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[40] Source: Gehrig, Matthias, Jürg Guggisberg, and Iris Graf. 2013. Wohn- und Betreuungssituation von Personen mit Hilflosenentschädigung der IV: Eine Bestandsaufnahme im Kontext der Massnahmen der 4. IVG-Revision [Living and support condition of persons receiving helplessness allowance by the disability insurance]. Bern: BSV. (http://www.bsv.admin.ch/praxis/forschung/00106/01326/)

Other systems to support DI and the development of community based support

One of the key systems that were noted as supportive of the development of community based and personalised support was the availability of personal budgets, direct payments or other individualised funding systems. This was true in those countries where deinstitutionalisation had already been completed in the main (Sweden, Norway, UK and Switzerland) but was also emerging as a supportive option in other countries such as the Czech Republic and Germany. In some countries there was specific support for helping people to live in their own home (rented or bought) - for example housing benefit in the UK and in Norway special favourable loans and support for buying or building their own home, alone or together with peers they chose to live with. Person-centred assessment and planning were also listed as facilitators of community based support in some countries. Special arrangements for accessible transport as well as systems to allow adaptations of housing and the purchase of equipment are available in Sweden, the UK and Czech Republic. In Italy benefits are also available for adapting homes to meet people's needs. In the UK, carers assessment, and although not as plentiful as really needed, the availability of respite, day provision and home help for carers has helped more people to be able to stay in the family home. However it is worth noting that in Norway and Sweden people are supported to move out of family homes as part of normal life transitions.

Active Citizenship

When thinking about active citizenship and community living there is substantial overlap between the concepts of security, autonomy and influence. There were a number of elements which were explored as part of the work package:

1. Do people have choice over where to live and who to live with?
2. Do people have choice over who provides support?
3. Are people involved in their day to day lives, taking part in meaningful activities and relationships?
4. Do people have freedom to move around their home and community, with support if necessary?
    a. Accessibility
    b. Transport
    c. Appropriate support
5. Do people have enough money to meet their needs and allow some community participation/inclusion?
    a. Paid employment
    b. Benefits
6. Do people have a role in their community?
    a. Caring/Volunteering role
    b. Taking part in community groups, church etc.
    c. Having a job
7. Do people have real choice and control over how they spend their time?
8. Can people live as independently as possible?
9. Are people safe in their homes and community?
    a. Abuse and victimisation
    b. Staff support

However very little information was available on most of these areas in most countries. As such Tables 6 and 7 below summarises the information available on the situation in each country with regard to active citizenship focusing on two more general areas – 1) Choice and autonomy with regard to living situation and support received and 2) Involvement of people with disabilities in their day to day lives, taking part in meaningful activities and relationships, engaging in their local community with choice and control over where they go, what they do and with whom?

Research on the situation of people with disabilities (either by independent bodies such as universities or in the form of government reports) is only available in a small number of countries – primarily the UK, Ireland, Norway, Sweden and a few studies focusing on personal budgets in Germany. In some cases it was possible for those completing the templates to describe the general situation but in others there is very little information available.

From the information that is available it is clear that all countries still have some way to go before all people with disabilities are really experiencing active citizenship. Of course, in all countries, there will be some people, usually those with less severe disabilities who have support from others or who can advocate for themselves, who will be living an active life in their own home and in the community. However in all countries those with the most severe disabilities, in particular those with intellectual disabilities, have the least choice, autonomy and participation in community life. Those with physical and sensory disabilities are likely in all countries to have more choice and control over their lives.

Choice of where and with whom to live and support received

Information about the number of people who have choice over their living situation was only available for the UK and Ireland and only for people with intellectual disabilities. In Ireland a survey found that more than half of people with ID had no choice in whom they lived with or where they lived. In the UK similar figures have been reported - almost 50% of people report no choice in where they live and 1/3 of people report no choice in who they live with.

In the other countries it was generally found that, apart from where people were receiving personal budgets or had a service in the form of personal assistants, choice over where and with whom to live was limited, especially for those with more severe levels of intellectual disability. However in Norway and Sweden choice about living situation and support depended very much on the level of service required. In Norway 22% report that they have taken part in decisions on where they live, and 15% on whom they live with (Söderström & Tøssebro (2011). Those who needed more intense support were often unable to access a range of choices – being steered towards a group home with only one group home available locally. In the Czech Republic, in principle people have choice over where they live but currently this is still difficult to achieve.

Involvement of people with disabilities in their day to day lives and in their local community

Very little information was available on the extent to which people were actively involved in their lives and their community. In Norway, as in the UK, it was commented that there had been a clear change in how often you would meet someone with an intellectual or multiple physical disability in the street, stores, on public transport or in the local swimming pool. However even in the UK, Norway and Sweden where deinstitutionalisation had happened earlier, people with disabilities were less likely to have a job or to be involved in volunteering or other community roles, with very few people with intellectual disabilities in particular having a job.

Only in the UK was there any research on how people with disabilities (in this case people with ID) spend their time and the quality of the support that they receive to be actively engaged. A study by Netten, Beadle-Brown *et al*. (2010) found that people with intellectual disabilities in residential care (average size of service was 7 places) spent only 40% of their time engaged in any form of meaningful activity and only received any contact from staff for 12% of the time. That is only about 8 minutes in every hour. This situation was only slightly better than older adults (generally aged over 80) in large care homes. This level of engagement and isolation is generally commonly observed across a number of studies (reviewed by Mansell and Beadle-Brown, 2012) in the absence of, or prior to the implementation of person-centred active support (see below).

In countries where the primary provision is still institutional care (Serbia, the Czech Republic, Germany and Italy), achieving community presence, let alone community participation and active citizenship, can be difficult. Where people did get involved in their community, this was often seen as down to personal will and the level and quality of support someone gets.

There were also examples provided of how, despite legislation to the contrary, many people with intellectual disabilities and mental health problems in group homes or even in apartments do not have freedom over their lives. For example in Sweden a report found that areas of their homes were locked, fridges and cupboards were locked and the front door was locked when too few staff were around. It was also found that staff were using restraint with people with challenging behaviour, despite it being prohibited by law to do so.

The accessibility of buildings and transport ranged across the countries but in most countries there remained some limitations in terms of accessibility especially for those with more severe disabilities. In Germany people with disabilities reported more difficulty accessing a number of community facilities than people without a disability, although in general people appeared to be able to get to all the facilities relatively easily. However it as also noted that issues of accessibility are often only considered in terms of physical access e.g. to buildings. In Serbia it was reported that little thought is usually given to accessibility of information and easy to read documentation.

In some countries such as the Czech Republic, people with more severe disabilities are excluded from political participation, with some parties considering those without legal capacity to be ineligible to be a member of the party. In Serbia people without mental capacity cannot vote or become a member of an association.

Finally in the UK, one issue that has received much attention recently is the issue of people with disabilities being the victims of disability related hate crimes or victimisation. This has been raised particular in relation to people with intellectual disabilities after a number of very prominent incidents covered by the media. Beadle-Brown *et al*. (2013) reported that over one third of people with intellectual disabilities are currently experiencing or have experienced victimisation from others in the community.

Polices and systems to support active citizenship

In most countries the policies and mechanisms are already in place to promote more autonomy and active participation of people with disabilities.

With regard to the issue of security, in the Czech Republic, policy states that people's services must be secure but very little further information is available.

The mechanism that was seen to be the most important for promoting active citizenship was the availability personal budgets or personal assistance schemes where people could have more choice over where they lived, who they lived with and who supported them, as well as their day time activities. Personal budget and personal assistant schemes are already available in Norway, Sweden, UK, Germany, and in their infancy in the Czech Republic. In all countries apart from the UK personal budgets and personal assistance is much more commonly or in the case of Germany exclusively, given to people with only low level support needs. Those who have higher support needs generally access other types of specialist services. In Norway and Sweden this is likely to be a group home. In Germany, the default for people with more severe disabilities is institutional care.

In Germany and the UK there is research into the impact of personal budgets. In Germany 80% of people said their lives improved after receiving a personal budget, with people experiencing more choice over the activities they participated in over their assistant. In the UK, there is also evidence of the benefits of personal budgets. However, there is emerging evidence from research by Chris Hatton and colleagues that many people have a council managed personal budget and that this accounts for the rise in the number of people having a budget. For many of these people there is no difference in their actual situation – the money is just handled differently.

The other mechanism that was important in some countries was individualised assessment and planning, which helps to promote more focus on the individual and helps people to express their own wishes and preferences. However, for people with more severe disabilities, this alone is not enough to ensure that people can have choice and control and active involvement in their lives.

Most countries had policy that specified that public buildings and spaces and public transport had to be accessible to people with disabilities, although implementation of these policies were at different stages in different countries. Disability Discrimination or equality Legislation also often supports the employment of people with disabilities.

In the UK, Norway and Sweden, benefits and other forms of funding or favourable bank loans were available to help people to rent, buy, build or adapt their own home to meet their needs. In addition people can get support to facilitate day time activities, leisure activities etc. There are also voluntary organisations that try to support people to access a range of opportunities, including holidays, sports etc. Sometimes these are specific for people with disabilities and sometimes with other people without disabilities. There are also organisations such as independent living organisations that support people to manage personal budgets, to fight for their rights and also in some countries there are advocacy schemes, as well as self-advocacy and disability rights organisations.

Finally, research in the UK has focused on exploring what is needed to promote much more active citizenship, in particular for those normally marginalised and isolated. A range of studies going right back to the start of the deinstitutionalisation process in the UK, found that what was important was what staff do – their care practices. Mansell and Beadle-Brown (2012) review this literature and describe the process of active support – a way of enabling and empowering people to live fuller lives at home and in their local community.

Barriers to Active Citizenship

The "menu" of services to choose from is often limited, either because the country is at an early stage of deinstitutionalisation or because of cuts in funding due to the financial crisis - the lack of funding is usually seen in lack of staffing, restricting people's options in terms of housing and community involvement. But the number of staff available can also be used as an excuse by staff (e.g. in Sweden and the UK) – the issue is often the lack of the right knowledge and skills in staff to support people.

Bureaucracy around personal budgets can also be a barrier to people accessing those – in the UK this was seen as too great even for many parents to manage.

Deprivation of legal capacity was seen as an issue in some countries. Guardians and in Sweden, trustees, are often appointed to help people manage decisions and to protect them from exploitation and abuse. In principle this should be a facilitator if the guardian is really acting as an advocate on the person's behalf with the knowledge of what the person might want to do. However in reality guardians (and the lack of progressive legal capacity policy) can also limit people's opportunities to make decisions.

The views and actions of other members of the community can also be a barrier to active participation although research on this is limited. In the UK there is currently research looking at hate crime and victimisation of people with disabilities. Beadle-Brown *et. al*. (2013) found that just over 1/3 of people had or were currently experiencing victimisation in the community. Their families and even their paid support are often living in fear, adapting what they do and when they do it to avoid incidents of bullying or other forms of victimisation.

Table 6 Active citizenship, the policies and systems – choice of where to live, who to live with and the nature of their support

	Situation	Policies and systems to support active citizenship	Barriers to active citizenship
Do people have choice over where to live, who to live with and who supports them?			
Norway	The amount of choice people have about where to live and who to live with depends on the level of support or service required. People with ID that receive moderate to extensive services have little choice about where to live and with whom[41]. For people moving into a house that is not rented from the municipality, the choice of where to live is dependent on market forces as for everyone else. Less evidence for people with mental health difficulties but in general choice is dependent on the level of service and type of service needed rather than on diagnosis. Most people have little choice in the service they receive. Parents can choose to support the person at home but have little choice about what type of service they get if they want the person to have a home of their own. The spread of organising services as personal assistance is helping give people more choice as they can employ someone to support them in their own home, with help from parents or guardians if needed.	The option of organising the service as personal assistance with the support of family or guardians if needed, promotes more choice. Most political parties in the parliament have signalled that they will support a law that gives people the choice of organising services as personal assistance. There are also support systems to help people buy their own home – schemes in the National Housing bank which allow people with difficulties finding a suitable property in the housing market to apply for a favourable load and support to buy or build their own home, alone or together with peers they choose. Even those with extensive service needs can access for this support with housing. In principle all services are supporting living in Norway – housing and support are independent. In 2013 a government White Paper[42] on services for people with ID stressed the importance of self-determination, setting it up as the new ideology instead of normalisation. However there was very little discussion about what was needed for implementation (by government or by anyone else).	In principle people can make choices about where to live if they rent from local government but in reality the availability of living arrangements makes choice impossible. There is rarely more than one option available. The possibility to buy or build on the open market is restricted by income (as for the rest of the population) – the economic support available is good but requires extensive organisation which is too much for most people, including many parents, to organise. People also fear that if you buy or build on the open market you will not get the services you need. Parents report that municipalities are more reluctant to support private projects now and in particular appear to be reluctant to commit to any services/support packages before people buy or build a home, usually parents buying for their son/daughter – which makes such a venture risky.

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[41] Söderström and Tøssebro, 2011

[42] Melding til Stortinget – white paper no 45 (2012-2013) on services for intellectually disabled people

Sweden	Individuals who are awarded a personal assistant have the right to employ the assistant of their choice (or to select the assistant if they prefer the municipality to be the formal employer). The disabled person can also choose to have the assistance arranged by a user collective or a private provider. The person also has the right to decide what kind of help the assistant should give and in what way. In contrast to social assistance, which is needs-tested, disability services are specific social rights based on statements in the law.[43] However it is difficult for people to choose the group home or other special residences that they want to live in and even more difficult to choose who they live with or the daytime activities that they do. However becoming more common for parents of people with ID to start co-operative group homes, with permission from the municipality, especially where the people have been to school together and know each other well. The parents then have a say in who lives in the home. This usually means that the people live in their own apartments in the same building supported by staff residing in a nearby apartment. The co-operative receives financial resources to run activities[44]. People can have a guardian, mentor or trustee to help with decision making. The number of guardians, trustees and mentors appointed has increased since 2006. However it is not unusual for people to appeal to the district court to have the decision of the chief guardian	Personal assistance scheme. Specially adapted housing support is available so that people can live in an ordinary home in the community. People with mental health problems may have access to a personal agent to represent the person and help them cope with everyday life, liaising with other agencies etc. This has been reported to be popular with people with mental health problems[45]. Guardianship is intended to support the individual in decision making about all areas of life and is strictly regulated. However the district court can also appoint a mentor or trustee (at the request of the chief guardian, the individual themselves or a relative) but have to hear the individual before any decision can be made. A mentor or trustee helps the person in decision making about major life decisions, contact with authorities, financial decisions etc. A mentor needs the person's consent before legally binding actions are taken. A trustee does not.	Lack of services available is an issue that reduces choice about where to live/what support to have. The freedom to choose where to live may sometimes be restricted by the fact that management insists or "offers" people with similar needs, or people in the same age cohort, the opportunity to live together in the same group home.[46] The choice of the individual is also restricted by the fact that it rests with the municipality to plan and decide where to locate group homes. Therefore, the individual's choice is more limited compared to other people.[47] Furthermore, it can often be a complicated and time-consuming process if the person living in a group home wants to move from one municipality to another. In such cases a new application must be submitted and the needs of the individual must be described and assessed again in the new municipality. The same difficulties may occur if the person lives in a specially adapted apartment; then the new municipality must find or adapt a new apartment, which may take some time. As noted in the first column, the process of guardianship and trustees may also limit people's autonomy in a range of decisions

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[43] Swedish Code of Statues (*Svensk författningssamling,* SFS) *1993:387* Article 7, Law on special support and services for persons with disabilities (Lag om stöd och service till vissa funktionshindrade).

[44] www.bok.nu/book.php?bookid=662435

[45] Swedish Government Official Report (SOU) 2006:100) Ambition och ansvar. Slutbetänkande av nationell psykiatrisamordning' Ambition and responsibility. Final report by the National Psychiatry Coordinator) , p. 340.

[46] Ibid., p. 33.

[47] Ibid., p. 38.

	changed, indicating that it is difficult to get a balance between supporting and protecting the individual and respect for autonomy.		including where to live.
UK	Less than a third of people with ID have some choice of who they live with, and less than half have some choice over where they live. Those with a personal budget or direct payment in theory have more choice over where they live, whom they live with and who supports them. Some really good creative practice exists involving those with even the most complex needs in decisions about their lives including the selection of staff. This also occasionally happens in group homes but is rare. Although having a personal budget should provide more choice and control in this area, as noted above, the largest proportion of personal budgets, especially when given to people with intellectual disabilities, are council managed budgets – this means that the council keeps the money and the person is asked about what they want and these wishes respected if appropriate services are available. In reality for many people life with a council managed personal budget is not different to those who do not have a personal budget. For many people life does not change much in terms of autonomy and other outcomes for those on a council managed budget. [48]	In general policy in the UK has been driving for personalisation including the use of direct payments and later personal budgets for almost 20 years. Increasing choice and control is seen as central to helping people with mental health needs obtain care which suits their needs and lives. The drive to personalisation, self-management, and the promotion of choice continues to receive government support, with choice and control, use of personal budgets, and support to live independently being central to the governments' strategy for ensuring that people with disabilities, including psycho-social disabilities, achieve parity with non-disabled people in their everyday lives (DWP, 2013). Specific policies to support include: • Independent Living Strategy 2008. (A cross-government strategy including employment, transport, health, education and communities. This has now been superseded by two publications from the Coalition government.) • Caring for our future (2012) • Fulfilling Potential (2013) Valuing People (2001) and Valuing People Now (2009) The "supporting people" scheme funded people who were living in their own homes – now stopped as too expensive but had a huge impact on the number of people renting or owning their own home. Finally the REACH standards were developed to help organisations to monitor the quality of supported	There are a large number of issues that restrict people's choice and control over their living and support situation: Some local authorities are refusing in times of financial crisis to fund people in supported living type arrangements. They meet their personal budget targets by switching people onto a personal budget but the person stays in their group home etc. In many local authorities there is a lack of good (or any) services to choose from. Managing personal budgets is very bureaucratic and so many people choose not to do so. Still a culture where people (in particular parents) feel they should be grateful for what they get and not complain for fear of losing any service, although this is changing. Person-centred planning is often not independently facilitated but facilitated by services involved in supporting the individual – this often means that the options are limited to what already exists rather than what it is possible to develop. Organisations often employ staff centrally and the staff is then allocated to a service. This is changing as noted in column 1 but this is not widespread. If living in supported living services, people theoretically have the ability to stay in their

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[48] http://www.in-control.org.uk/media/138273/poetsummaryfinal.pdf

		living and focus heavily on the fact that to be real supported living, people have to have choice over where they live and who they live with.	house and change their staff but in reality this isn't always possible as many services of this nature were group homes that deregistered in order to access Supporting People funding. In reality people in this setting have no more choice and control than in other types of services.
Czech Republic	In principle people should have choice over living situation and support[49] but there is no report available to allow comment on how much this happens.	The National Plan, sets out the possibility of personal budgets. Supporting self-determination of service users is one of the key elements related to changes in institutional and community living (empowerment of service users is codified in the Social Services Act 2006).	One barrier comes in the form of the current mechanism for monitoring quality of social services including extent that people have choice. There is limited provision for quality assurance due to cuts in public spending. The Government merged social affairs administration (previously also responsible for inspections in social services) together with labour administration. The Government Board for People with Disability reported that this step has a negative impact on social service quality inspections. Notably there is an insufficient number of staff qualified for social services quality inspections. At the end of 2012 the regional offices of the labour office employed as "inspectors of social services" only 43 staff in total for whole country. That is 3.07 persons/inspectors per regional labour office.[50]
Serbia	Very little information is available here. However it is clear that not everyone has choice over where they live and certainly not people with more severe disabilities, lacking mental capacity. People with physical and sensory disabilities have more choice then those with ID	Strategy for Development of Social Protection (2005), Strategy for Improvement of Position of Persons with Disabilities in the Republic of Serbia (2007), Law on Social Welfare (2009), Law on Social Protection (2011), Rule Book on the conditions and standards for the provision of social welfare services	Main barrier is deprivation of legal capacity mostly affecting people with ID and psycho-social disabilities. Placement in social care homes or psychiatric hospitals is considered as voluntary if approved by a legally appointed guardian, leaving people under

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[49] Czech Republic. Social Services Act No. 108/2006 Coll.

[50] Government Board for People with Disabilities, Czech Republic. *Minutes Meeting, March 11, 2013.* http://www.vlada.cz/cz/ppov/vvzpo/zasedani-vyboru/zasedani-dne-11--brezna-2013-104228/

	and psycho-social disabilities	(2011) – these policies are designed to develop better lives for people with disabilities but are not yet implemented.	guardianship without any choice.
Ireland	21% in group homes, 43% in family and 5% in semi-independent apartment - found that 58% of people had no choice whom they lived with, and 50% of people did not choose where they lived[51].	The national strategy 'Time to move on from congregated settings' allow people to choose where they want to live and what services they receive. The National Advocacy Services supports people with disabilities in decisions making including living arrangements, for people with psycho-social disabilities there is a peer advocacy service although it is said that the Irish legal system uses the substitute decision making for people with disabilities known as the word of court system.	No personal budget scheme established yet. Process of deinstitutionalisation still in progress.
Germany	The 'Persönliches Budget' requires the participation of the disabled persons in various stages of the process and therefore fosters their right to choose (Metzler et al., 2007: 154). About 90% of survey respondents reported that they were content with their personal budget. About 80% of the participants stated that their life had improved (Metzler et al., 2007). Those receiving personal budgets can choose their staff. However only a very small number of people have personal budgets – generally those who have lower support needs. data from two projects available: 42% with psycho-social problems, 31% with cognitive impairments, 19% with physical disability and 7% with other form of impairments Other research[52] has found that Personal Budgets were perceived very positively, enabling the persons with disabilities more opportunities for choices with regard to	Social Code Book IX, section 9 "Wunsch- und Wahlrecht der Leistungsberechtigten" (right of choice). The support measures and services are supposed to align with the individual wishes and choices of the client, considering his or her personal situation. Social Code Book IX, section 17, paragraph 2-6 "Ausführung von Leistungen, Persönliches Budget" (Personal Budget) Direct payments have been gradually introduced since the new rehabilitation and participation law came into force in 2001; they take the form of personal budgets and have become a legal right since 2008. It is very likely that personal budgets will further promote the implementation of independent living, as the lump sums are granted, distributed and managed according to individual needs and life situations. On the other hand, there are fears that the benefit could	Only a small number of people have access to personal budgets. Most people with more complex needs in particular still receive services through institutions or large group homes.

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[51] http://www.tcd.ie/niid/pdf/IRN%20revised%20folder/PDFs/Where%20we%20Live%20Report%202010.pdf

[52] From 2003 to 2007 a scientific research project 'PerLe' (Wacker, Wansing, & Schäfers, 2005) investigated the use of Personal Budgets in 'stationäres Wohnen' living arrangements for persons with cognitive impairments. Of 24 persons with disabilities living in a 'Wohnheim' 17 (up to 20) persons participated in the project. Schlebrowski (2009) conducted interviews to explore the perspectives of the persons with disabilities and the changes they perceived.

	activities, choice of assistants. Schlebrowski furthermore states that the use of the Personal Budget changes the relationship between the persons with disabilities and the assistants. The Personal Budget requires cooperation between both partners and asymmetries in power shift to more symmetry. In addition the Personal Budget strengthens the citizenship status of persons with disabilities because it improves the political rights of persons with disabilities as it permits exercise of influence. In addition the role of the persons with disabilities changes from a passive consumer to a more active role. With regard to daily life, this shifts from service provision [‘Versorgung’] to a more individual lifestyle [‘individuelle Lebensführung’][53]. The disability report of the German government [‘Teilhabebericht der Bundesregierung’] states that whereas about 15% of the persons with disabilities perceive their opportunities for self-determination as low, only 10% of the persons without disabilities report to perceive their opportunities for self-determination as low. (Bundesministerium für Arbeit und Soziales, 2013: 182)	be used by local authorities in order to cut down costs, and that it could lead to new forms of dependencies (eg. within families and/or in guardianship). These fears should be taken seriously; independent research is needed in order to evaluate disabled people's experiences with this new instrument. (Waldschmidt, 2009: 2) Social Code Book IX, section 63 „Klagerecht der Verbände“ (right to sue of the disability organisations) Gesetz zur Gleichstellung behinderter Menschen (Disability Equality Act). Persons with disabilities can pass their individual rights to legal proceedings to an organisation which represents persons with disabilities. This organisation is entitled to go to court on behalf of disabled people. Personal Assistance, Verordnung über die Mitwirkung der Bewohnerinnen und Bewohner in Angelegenheiten des Heimbetriebs (Heimmitwirkungsverordnung) (regulation of participation in residential homes) Bundesverband Interessenvertretung Selbstbestimmung Leben (federal interest group independent living). Since the concept of personal assistance was originally developed from activists of the disability rights movement, it involves the philosophy that disabled people must be in control of these services (ISL 2001). The so called ‘employer model’ implies that only services which follow the following principles are called personal assistance services: disabled people control and manage staffing. They close contracts with their assistants and decide about the working conditions including the salary. Disabled people are free either to function as employers or use the service of a personal	

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[53] Schlebrowski, (2009)

		assistance agency. Disabled people control the ways in which personal assistance is carried out. They instruct their assistants and decide which services are carried out and which not. Disabled people are in control of the services' budget and its management. They are free to decide about the organisation and practice of personal assistance according to their needs and wishes. They are those who decide in which room or at which place assistance is carried out. Personal assistance can take place in private homes, in the public, at the workplace, at a holiday resort, paying visits to friends etc. (Waldschmidt, 2009)	
Switzerland	Since the beginning of 2012, personal budgets are available to persons with disabilities in addition to helplessness benefits. Advocacy groups have identified some issues regarding the implementation of the personal budget that seem to limit its overall positive impact (e.g. insufficient coverage of costs).[54] The results of an ongoing official evaluation of the impact of personal budgets are due for 2017 (interim reports will not be published).[55]		
Italy	Small number of people with physical disabilities and hearing or visual impairment have more freedom and choice but people with intellectual disabilities have less choice about place of living. No research about people's choice	Advocacy Groups acting as a peer support within the agencies for independent living. Centres for independent living and independent living services	Same things that were identified within policies or system as support measures or services were also identified as obstacles when missing, not implemented or not covering. As above, lack of independent living scheme, architectural barriers, inaccessible transport and lack of participation in the labour market and therefore income.

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[54] Zentrum für Selbstbestimmtes Leben, http://zslschweiz.ch/uploads/2013/1378899712_fehler-assistenzbeitrag.pdf)

[55] Federal Social Insurance Office, http://www.bsv.admin.ch/praxis/forschung/00106/01326/index.html)

Table 7 Active Citizenship across the participating countries – involvement in day-to-day life in the community

Country	Situation	Policies and systems to support active citizenship	Barriers to active citizenship
Are people involved in their day to day lives, taking part in meaningful activities and relationships, engaging in their local community with choice and control over where they go, what they do and with whom?			
Norway	The employment rate of disabled people is in general low and people with severe cognitive disabilities or mental health problems rarely have employment the same places as other people. One also sees increasing segregation in schools as children grow older. Very few are segregated as small children, but this gradually changes as they get older (Wendelborg, 2010). The type of segregation is however "special class" or special school, but not removal from the community. However, if one asks about the opportunity to use the regular public transport, swimming pools, stores, parks and playgrounds, there are few or fewer barriers. Since around 1990 (after the closing of institutions for intellectually disabled people) one see a clear change regarding how often you meet someone with an intellectual or multiple disability in the street, stores, busses or swimming pools. People have access to activities that sometimes are for disabled people in a community setting (but only for disabled people) and sometimes activities where disabled people are with nondisabled peers. This could be sports clubs, Lions, and also the local government cultural or leisure initiatives.	Helse- og omsorgsloven - People have access to leisure assistance, personal assistance. Some voluntary associations organise sports activities, clubs and other activities with support from local government leisure and cultural initiatives.	One barrier can be the lack of available staff and also the fact that often normal activities in the community are not well adapted to the needs of the disabled individual. As such there are no legal barriers, but practical.
Sweden	People with intellectual disabilities and mental health problems living in their own apartments or in special residences are not, according to the law, restricted in their freedom to come and go and to socialise with whoever they like. They are free to spend their money as they please (unless they have a trustee). However, in many special residences there may be unlawful restrictions. In a monitoring report from the National Board of Health and Welfare (2010) the board observed restrictions to freedom in special residences for people with intellectual disabilities in some municipalities. Collective spaces were locked, refrigerators had padlocks and front doors were locked	In policy and practice there has been an increasing emphasis on consumer rights and the use of the personal assistance scheme in services for people with ID. People can have staff matched to their needs, and also have access to leisure assistance, employment support etc. There are also some user organisations to educate and support people in managing personal assistance and to help people access legal support and exercise their social rights – for	Not detailed although issues around available and training of staff were raised in the template.

	when there were too few staff. Conflicts between staff and users were also reported, resulting in users being “wrestled to the ground”.[56] Although forced treatment and interventions imposed on people living in group homes is strictly forbidden according to Swedish welfare law, and is contrary to the UN CRPD Articles 16 and 17, violence, abuse and disrespect for the disabled person’s integrity do occur.[57] Concerns rose in the media and in public debate deal with how to allocate sufficient financial resources to disability services so that staff shortages are prevented (since this may function as an excuse for restricting the liberty of people with disabilities) and how to improve the staff’s disability awareness, education and occupational status. The Handisam report[58] on the implementation of the Disability Policy 2011-2016 explored whether the experiences of people with disability matched policy. The report found that in 2013 there were differences between the experience of people with disabilities and those without: Fewer people with disabilities go to the theatre, concert or museum Less than one in five cultural institutions have dealt with all easily removed barriers in the physical environment 7 our of every 10 busses, trams and trains have low floors to allow wheelchair access 1 in three people with disabilities were dissatisfied with the level of accessibility of restaurants, café’s and bars Only 2/3 of municipalities had accessible sports facilities.	example: JAG (Equality, Assistance and Community Jämilikhet, Assistances och Gemenskap), STIL (Stockholm Independent Living) Swedish National Association for persons with Intellectual Disability (FUB).	

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[56] National Board of Health and Welfare (*Socialstyrelsen*) (2010) *Social tillsyn. Länsstyrelsernas iakttagelser under 2008 och 2009*, Social monitoring. Observations by County Administrative boards during 2008 and 2009) pp. 33-34.

[57] In the media cases are reported from time to time. One example is reported from a group home for people with intellectual disabilities in Gothenburg, describing how staff shouted and swore at residents and pushed them into their private rooms. See: *Göteborgs-posten* 26 November 2010, pp. 4-5.

[58] http://www.handisam.se/Global/Rapporter/Hur%20%c3%a4r%20l%c3%a4get%202013%20Uppf%c3%b6ljning%20av%20funktionshinderspolitiken_130517.pdf

UK	According to the Office for Disability Issues over a quarter of disabled people say that they do not frequently have choice and control over their daily lives (ONS Opinions Survey 2011). Disabled people remain significantly less likely to participate in cultural, leisure and sporting activities than non-disabled people. Latest data shows disabled people are more likely to have attended a historic environment site, museum or gallery than in 2005/06. However disabled people are less likely to have attended a library over the same period. Disabled people are less likely to engage in formal volunteering. In 2010/11, 23 per cent of disabled people engaged in formal volunteering at least once a month, compared with 25 per cent of non-disabled people. Many people do but those with intellectual disability less likely to vote etc. Very dependent on the staff who support them to facilitate. Many people spend much of their time at home or when they get out they go to special activities for people with disabilities. A recent study by beadle-Brown et al. found that 75% of people lived in a home where everyone was observed to be sedentary all of the time that observers were present. People with more severe disabilities were less likely to get involved in day to day activities around the home and in the community. Support for community participation was poor in many places making it difficult for people to be empowered and have control over their lives. 46% of people registered as disable work (compared to 74% of people without disabilities[59]).However increase in number of disabled people working since 2002. People with physical disabilities are more likely to have a job. In 2010/2011 - 6.6% of adults with learning disability - in some form of paid employment.[60]	Disability Discrimination Act - dictates accessibility of buildings, transport etc. Reasonable adjustment at work etc. The policy mentioned earlier (Independent Living Strategy 2008, Caring for our future (2012) and Fulfilling Potential (2013)) all speaks to people with disabilities being as involved as possible in all aspects of their lives, have choice and control and full access to their community. Specifically for people with intellectual Disabilities, the white paper, Valuing People Now (2009) also sets out the vision for those with more complex needs having access to employment etc. Department of Health funded a project to support the development of work and other opportunities even for people with the most complex needs [62] The availability of personal budgets and the use of person-centred planning also help people to have more say in their day to day lives. Especially effective for those with physical and sensory disabilities. Charities and volunteer schemes also exist to give people new or regular opportunities to take part in activities, go on holidays etc. There are also supported employment agencies that help people get a job. In the UK, the media is an important tool for driving change – it only takes one scandal to make people pay attention to what is going on and to start the process of change (which can be slow	Rationing of support means that only those with the highest level of need get substantial services. People have no right to any particular service. This means that many of those who are more able do not get the help they need to make the most of the opportunities available to them. Focus is often on keeping people safe. Research has shown that for people with more complex needs personal budgets and person-centred planning and even having staff are person-centred in their approach is not enough – staff need the right skills to enable and empower people not just care for and control people. Mansell and Beadle-Brown (2004 and 2012) argue that staff needs to be able to use person-centred active support to really help people make the most of the opportunities available to them. There are few qualifications in the UK that provides staff with these skills and no requirement at present for staff to use this type of approach. Training is available but not all staff and not all organisations will know about it or choose to attend. Although under revision currently, the standards and processes for inspection of health and social care services have focused primarily on processes and less on outcomes for people with disabili-ties.

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[59] (http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php

[60] Emerson et al. (2011) Learning Disability Survey.

[62] http://base-uk.org/sites/base-uk.org/files/[user-raw]/11-06/sustainable_hub_of_innovative_employment_for_people_with_c.pdf

	About 1/5 of people with disabilities report having difficulty with public transport[61]. For people with ID and autism transport was a place where harassment and victimisation could occur (Beadle-brown et al., 2013). But there has been an increases in accessible buses since 2004/2005.	but non-the-less happens).	Inspectors do not always have the skills or experience necessary to know whether support is good or bad.
Czech Republic	There are no studies about people with disabilities being involved in community activities. However it is evident from several studies that people with intellectual disabilities without legal capacity are excluded from both passive and active political participation. Some political parties even consider these people as not eligible to their membership [63].	Helping people with disabilities in social care to choose how much they participate in daily living activities in residential facilities is one of the requirements in the Social Services Act. From the perspective of that act, people with intellectual disabilities are no longer regarded as passive recipients of care, but should be active partners manifesting their will. Section 88.f of the act requires the service provider to make an individual plan for a service user according to his or her personal goals, needs and competences. The Employment Act 2004 came into force in 2004. With a section devoted specifically to people with disabilities, this law is the most important legislation concerning the employment of people with disabilities. The Employment Act 2004 introduced a number of important changes to employment services for people with disabilities, and showed a positive shift towards the social inclusion of people with disabilities. It elaborated relatively new employment services, programmes and policy instruments. Importantly, it also provides for state financial support for the employment of people with disabilities on the open labour market, and not only in sheltered workshops. The Building Act and usage of buildings recognises barrier-free solutions to be in public interest. The Building and Construction Authority	Deinstitutionalisation at an early stage – personal budgets are in their infancy.

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[61] (http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php).

[63] Šiška, J. (2013) ANED *Report on Political Participation of People with Disabilities. Czech Republic. Working Paper.*

		can, under the provisions of the Act, order the owner of the construction, building site or developed area to arrange for its barrier-free access and usage. In addition, only such products, materials and constructions may be used in the building which will enable the due usage of the building including its barrier-free usage if the building has been designed as such. The Implementing Decree on Building Documentation (Decree No. 499/2006 Coll., on Building Documentation) comprises conditions and requirements for clearly defined and controllable solutions of buildings in terms of barrier-free access and usage by persons with limited mobility and orientation, both in the text as well as drawings sections. The Decree on General Land Use Requirements (Decree No.501/2006 Coll., on General Land Use Requirements) determines conditions for designing public areas so as to allow their barrier-free usage. The Decree on General Technical Requirements for Barrier-Free Usage of Constructions (Decree No. 398/2009 Coll., on General Technical Requirements for Barrier-Free Usage of Constructions) specifies general technical requirements for buildings and their parts so as to ensure their usage by persons with mobility related, visual, hearing and mental disability, the elderly, pregnant women, and persons accompanying a child in a pram or a child under the age of three. In spite of the fact that the improvement of accessibility of houses and flats should have a positive effect on both economic and social aspects, there certainly still remain some gaps in ensuring barrier free access.	

Serbia	Some groups of people with disabilities do play an active role, in their community but some do not (in particular people with ID and with psycho-social disabilities). Accessibility is perceived only as physical access to a certain facility. Accessibility of information and easy-to-read manuals almost do not exist. People deprived of legal capacity cannot vote or even become members of an association. Active participation of people with disabilities remains on a very low level and usually depends on personal will and the support a person gets.	The Law on Professional Rehabilitation and Employment of Persons with Disabilities (2009) that imposes an obligation of employers to involve people with disabilities so they have an active role in seeking and keeping their job. In practice the situation of people with disabilities at the labour market is hard as they are treated as objects of assessment. There is a legal requirement that transport and buildings should be accessible which has just came into a force (Rules on technical standards of accessibility (2013), but in practice they are rarely implemented. Reports mention that there are social service providers from the civil society sector, which support people in exercising their rights and freedoms.	The main obstacle the report mention is a lack of financial sources for Ngo providers and problem of financial sustainability.
Ireland	The right to equal access to all facilities and opportunities is currently denied by the use of substitute decision making for people with disabilities although the new reform is believed to correct this shortcoming of the law According to a survey from 2006 it seems that participation in community life for people with disabilities living in private houses is restricted in most areas: from jury service to having friends or family visiting. 56% of people with disabilities were experiencing difficulties in going to town, 53% going for holiday, 54% taking part in community life, 49% socialising in a public venue, 34% visiting friends, 34% attending religious ceremonies, 30% voting, 23% having friends visiting or visiting family or friends[64]. Another survey in 2011 conducted with people with disabilities found that of the people with ID who took part, 61% said they	Mental Capacity legislation is currently under development. However the new legislation although corrective of the present situation, continues to view mental capacity as a precondition for legal capacity therefore problematic from a human rights perspective	The Lunacy Act – there has been a process of substitute decision making for centuries. There is no adult protection policy.

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[64] Chapter 8 of the National Disability Survey available at http://www.cso.ie/en/media/csoie/releasespublications/documents/otherreleases/nationaldisabilityvol2/Chapters6-10.pdf)

	had access to their own kitchen, 88% said they could use the kitchen when they wanted to, 51% had their own bathroom, 86% had their own bedroom 35% had a key to their bedroom,66% said that other people did not come into their bedroom when they were not there. About half of people said they would change things about their homes and 16% said they would change something about the people they lived with. 34% said they would change something about the support they got - included things such as wanting to be able to go out in the evening with friends or just going out and making friends' people also wanted less support and more independence[65]. 84% said they had access to taxis and busses and 47% to trains.		
Germany	A study by Grammenos (2013) found that access to a variety of opportunities and facilities was not equal for people with and without disabilities. People with disabilities (in particular those with severe disabilities) reported more difficulties than those without in accessing: Grocery services Banking services Postal services Public transport services Health services Compulsory school However for none of these did more than 35% of people with disabilities report great or some difficulty, and usually it was less than 20%.	Social Code Book IX, chapter 13 „Unentgeltliche Beförderung schwerbehinderter Menschen im öffentlichen Personenverkehr", section 145-154 Persons who are registered officially as severely disabled can use the public transport free of charge or on small lump sum if their mobility is reduced (at least degree of disability of 80 and special qualifier) 1Gesetz zur Gleichstellung behinderter Menschen (01.05.2002) (Disability Equality Act) „The Disability Equality Act (2002) has brought the issue of accessibility to the fore. It provides rights and instruments in order to make gradually public places, public transport and communication (e.g. on the Internet) accessible for everybody regardless of a disability." Waldschmidt, 2009: 2) Social Code Book V, section 33 "Hilfsmittel" (auxiliaries) - If necessary the Health Insurance finances auxiliaries, e.g. assistive technologies for communication. Social Code Book IX, chapter 13 „Unentgeltliche	

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[65] http://www.tcd.ie/niid/pdf/IRN%20revised%20folder/PDFs/Where%20we%20Live%20Report%202010.pdf

		Beförderung schwerbehinderter Menschen im öffentlichen Personenverkehr“, section 145-154 (free transport in public transport for persons with disabilities) Social Code Book IX, section 57 „Förderung der Verständigung” (promotion of understanding) - This section regulates the assistance or auxiliaries for deaf persons. Social Code Book IX, part 2 “Besondere Regelungen zur Teilhabe schwerbehinderter Menschen” - This part of the Social Code Book IX regulates the compensation for disadvantages for persons with severe disabilities (degree of 50 or more), such as tax relief, free use of public transport, parking spaces for handicapped persons etc. Social Code Book XII, sections 53-54 and Social Code Book IX, section 55, paragraph 2, sentence 7 - Transport services for persons with disabilities are financially supported. (Bundesministerium für Arbeit und Soziales, 2013: 318)	
Switzerland			
Italy	Accessible transport in urban and rural areas	Independent Living Services - supporting autonomy and self-determination of people with disabilities, New Technology Aid support from LA, Accessible transportation and barrier free access to environment (services, buildings).	Same things that were identified within policies or system as support measures or services were also identified as obstacles when missing, not implemented or not covering. As above lack of independent living services to all regions, limited access to community and transport, social negative stigma, lack of new technology aid for all the regions, lack of accessible houses.

Conclusions

Analyses of national data showed that there were very limited existing sources which provide a comprehensive picture about the living situation of people with disabilities and their participation in community life in any of the countries studied.

Living situation

Concern about residential social services for people with disability has traditionally and mainly revolved around people with disabilities having to live in large residential institutions. Using a very broad definition of a residential institution as an establishment in which more than 30 people live, institutions exist in all countries studied. However Sweden only has larger establishments in the form of acute services for people with mental health problems and in Norway only a small number of people with severe or multiple physical disabilities live in larger services, although in both countries a recent trend towards bigger or more clustered settings was reported. In the UK there were also still an tendency towards of institutionnalisation and in some cases re-institutionalisation for those with intellectual disability and challenging behaviour and for older adults. Cuts in public spending and changes in public governance were amongst the explanatory factors identified.

In some countries such as Norway, Sweden, Switzerland, Germany and the UK, people with disabilities are supported to live in their own home (on their own or shared with other people) with support, rather than living in a group home or other residential setting in the community. However, apart from in the UK, this option is primarily accessed only by those with less severe disabilities – people with intellectual disabilities in particular are more likely to be in group settings, or in the case of Germany, in institutions.

Policy and systems

All countries studied have national policies and legislation in support of the social inclusion, self-determination and deinstitutionalisation of people with disabilities. One of the key systems that were noted as supportive of the development of community based and personalised support was the availability of personal budgets, direct payments or other individualised funding systems.

Quality of life and active citizenship

A review of the literature on the impact of deinstitutionalisation demonstrated that moving people into the community is important to improving their quality of life in terms of privacy, material conditions and in some cases the size of people's social networks. However, it is not sufficient to produce a better quality of life in other domains, in particular with regard to participation, choice and inclusion as well as self-identity and access to community life. Research from the UK since the early 1970s has pointed to the fact that the key determinant of quality of life is how staff (or other people) support individuals on a day by day basis – this is obviously much more critical for those with more severe disabilities who rely on support to access many of the opportunities easily available to the rest of society. This has implications for deinstitutionalisation programmes and the training of staff more generally.

Very little information was available about active citizenship on most of the areas studied in most countries. From the information that was available it is clear that all countries still have some way to go before all people with disabilities are really experiencing active citizenship.

In particular, the social integration of people with disabilities remains generally very limited – again most pronounced for those with intellectual disabilities. Very limited data was available on the extent to which people were actively involved in their lives and their communities – although the data that did exist indicated that those with intellectual disabilities often spent their time isolated and disengaged. Even in the UK, Norway and Sweden where deinstitutionalisation had happened earlier, people with disabilities were less likely to have a job or to be involved in community activities than those without disabilities.

Having freedom to move around their home and community, with support if necessary, also depends on accessibility and acceptance of the community as well as the support they receive. The accessibility of buildings and transport ranged across the countries but in most countries there remained some limitations in terms of accessibility especially for those with more severe disabilities. It was also noted that accessibility is often considered in terms of physical access e.g. to buildings but less as an issue of accessibility of information. Being the victims of disability related hate crimes or victimisation particularly in relation to people with intellectual disabilities was also reported as a significant concern.

As noted above, the mechanism that was seen to be the most important for promoting active citizenship was personal budgets or personal assistance schemes where people could have more choice over where they lived, who they lived with and who supported them, as well as their day time activities. Research in Germany for example indicated that people with a personal budget experienced more choice over the activities they participated in and over their assistant. However as shown in the UK the actual situation of people who have a personal budget also depends on how the budget is administered and the skills of staff who support the individuals.

Individualised assessment and planning, which help to promote more focus on the individual and helps people to express their own wishes and preferences, were reported as a useful facilitator in some countries. However the range of services to choose from remains limited. The reasons reported were being at an early stage of deinstitutionalisation and therefore a lack of community based services established and cuts in funding due to financial crisis.

In summary, those people with less severe disabilities who have strong families or advocates and are living an active life in their own home and in the community, are likely to have more opportunities and support to exercise active citizenship. However in all countries those with the most severe disabilities, in particular those with intellectual disabilities, have the least choice, autonomy and participation in community life.

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