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

Deliverable 6.3 (D6.3)

Transitions from institutions to community living in Europe

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Abstract

The main aim of the third deliverable from Work Package 6 of the DISCIT project was to develop recommendations to promote and sustain the development of community living for all people with disabilities. The deliverable begins by reframing information presented in deliverable 6.1 which focused on a review of the literature on the impact of deinstitutionalisation and the available information in each country about the living situation of people with disabilities. This deliverable demonstrated that moving people into the community is important to improving their quality of life such as privacy, material conditions and the size of people’s social networks. However, it is not enough for producing 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 requires. The available information demonstrated that all countries still have some way to go before all people with disabilities are experiencing active citizenship. Data which was available on the extent to which people were actively involved in their lives and their communities indicated that those with intellectual disabilities often spent their time isolated and disengaged.

Deliverable 6.2 drew on data from interviews with people with disabilities and suggested amongst other things, that increasing the inclusion of people with disabilities in society as active citizens requires increased accessibility of all community facilities and transport, change in attitudes and more awareness in the general public about disability.

Deliverable 6.3 draws, in addition to the findings from 6.1 and 6.2, on data from interviews with expert informants in the nine countries participating in DISCIT: the Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland, and the UK. These interviews explored the perceived problems inherent in current disability policy systems and possible solutions that promote community participation. Seven clusters of themes related to barriers to community inclusion were identified: 1. Policy and politics, 2. Funding availability and systems, 3. Co-ordination and organisation across levels of government and other agencies, 4. Attitudes and awareness, 5. Availability and flexibility of services and support in the community, 6. Influence of people with disabilities and their representatives, 7. Perverse incentives for the maintenance of institutional provision, contractions in the system and issues of definition and conceptualisation.

Finally, several facilitators of community living and Active Citizenship were highlighted including having a more holistic or comprehensive view of people and of disability support; better co-ordination between different levels of government; co-operation between DPOs to create a unified approach to strength the voice of people with disabilities; the involvement of people with disabilities in decision and policy making at all levels; having an individualised, person-centred approach; encouraging and if necessary supporting people with disabilities to

act in more influential positions; increased awareness about disability issues and what good practices might look like, especially for those with higher support needs; and developing alternative forms of funding to meet people's needs more efficiently and effectively.

The findings from all three of these data sources inform the twenty recommendations focusing on European, National and Local government as well as on Disabled People's Organisations and those providing services to people in the community.

Contents

1. Introduction

Living in the community (as opposed to an institution) is a central part of Active Citizenship. The DISCIT project has defined Active Citizenship 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) and 'Influence' (Exercising co-determination, individually or collectively, participating in self-organised, voluntary and political activities & in civil society). For all of these to be realised, being a part of society, physically as well as conceptually, is critical. The segregated, isolated nature of most institutions makes this very difficult and in many cases impossible.

As noted in Deliverable 6.1, Mansell, Beadle-Brown et al (2010)[1] 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. However, institutions are not solely defined by size or isolated location – Mansell and Beadle-Brown identified that it was possible to have institutional practices in small community based settings. Similarly, People First of Canada described 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" [2]

The early definitions of community care such as those put forward by the Kings Fund and the Ordinary Life programme in the UK were very similar to the concepts now inscribed in the UN Convention on the Rights of Persons with disabilities. The vision of community care was set out as:

- Using accommodation located among the rest of the population, which is adequate, appropriate and accessible to the individual
- Using the range of accommodation options ordinarily available to the wider population
- Enabling people, to the greatest extent possible, to choose where, with whom and how they live
- Providing whatever help is required to enable people to participate successfully in the community

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[1] Mansell, J. and Beadle-Brown, J. (2010) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, *Journal of Intellectual Disability Research*, 54, 2, 104–112.

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

More recently and in some conceptualisations, the vision of Community based services has come to refer to the approach to support, which entails the separation of support from provision of accommodation (sometimes called Supported Living). Ideally, support is provided to people within their own home, however in some countries this is not possible, as people do not have the income or support to own or rent their own property. As such, the key factor appears to be that people should have support, which facilitates access to employment, education, leisure or other activities in the community as well as enabling people to participate as much as possible in all the opportunities available around the home. People are involved in planning their support, such as where they live, who supports them and how they support their time. Overall, these services are intended to support people to live as full citizens rather than expecting people to fit into standardised models or structures.

The context for moving forward in this direction is the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) which spells out the right of disabled people to live in the community. Article 19 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.” However, campaigns for the human rights and freedom of people with disabilities are not new – such campaigns have been the focus of National and European disabled peoples´ organisations since the early 1970s.

Work Package 6 analyses developments towards community living related to a broader set of policy issues and discourses in Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK. Task and Deliverable 6.1, reviewed the research literature and other published and official documentation, legislation and statistics related to community living available for each country, using a template completed by partners in each country. Task and Deliverable 6.2 involved interviews with between 20 and 24 people with disabilities in each of the nine countries, within 3 different birth cohorts (1950, 1970 and 1990) and across four disability groups - those with visual impairments, those with mobility impairment, those with intellectual disability and those with mental health conditions or psychosocial disabilities.

This report is an outcome of Task 6.3 where the main aim was to develop recommendations to promote and sustain the development of community living for all people with disabilities. Being included in community settings requires the provision of adequate support in various community settings. Thus, this report must be read alongside other general provisions of the CRPD dealing with accessibility, employment, political participation among others.

The key research strategy used, in combination with the findings from previous deliverables, was a series of semi-structured interviews with informants from each country who were judged to have some expertise or knowledge around disabilities issues. We aimed to recruit people in each country who combined a good general knowledge about disability policy and the situation of persons with disabilities in their country and more specific and detailed knowledge in (at least) one of the areas focused on in DISCIT work packages. Eighty-four informants were interviewed across the nine countries. Those interviewed included representatives of innovative community care services and community based organisations, including disabled people organisations (DPOs) as well as representatives from official or government positions at national, federal/regional and local level. Some academic informants, as well as disabled people themselves were also included. Further information on the informants used for the current analysis is provided in Section 2.3 below.

The interviews aimed to establish the interviewees’ views on the situation of people with disabilities in each country and in particular, on the possibilities they have for achieving full and active participation in society. In addition, the interviews focused on gaining people’s opinions on the most important factors influencing the opportunities people with disabilities have and change over time. In particular, the interviews explored the role and influence of policy at different levels and of different actors in the system. Finally, the interviews were conducted with the aim to identify accomplishments, shortcomings and possible gaps in existing arrangements and potentials for improvements and better synergies, both horizontally and vertically.

2. Findings

This section brings together the key findings from the review-based research published in Deliverable 6.1 and the interviews with people with disabilities themselves published in Deliverable 6.2, along with some additional analysis from a larger sampler of interviews. It then goes on to present the findings from the interviews with other informants.

2.1 Setting the scene – reviewing policy, practice and research in each country

Deliverable 6.1 provided useful background information on developments towards community living. Analyses of national data reported by researchers in each country found that there were limited existing data, which provide a comprehensive picture about the living situation of people with disabilities, and about the support, they receive to promote their participation in community life in any of the countries studied. 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 (Mansell et al., 2007)[3], available statistical data suggested that institutions still exist in all countries studied. However, there are differences between the countries studied. In Italy, there were more people in institutions now than there had been in 2006/2007. Sweden only has larger establishments in the form of acute services for people with mental health problems and in Norway and Sweden only a small number of people with severe or multiple physical disabilities live in larger services. In both countries, a recent trend towards bigger or more

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

clustered settings was reported. In the UK, there was also still a tendency towards institutionalisation 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. Attitudes based on a primarily medical model were often associated with a need for change towards equality and a more holistic approach.

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), 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. Even where these options existed, previous research had shown that the majority of people did not have a choice over who supported them and even support was received. A large proportion in many countries did not even have choice over where and with whom they lived, even when they were paying rent for the house.

Regarding policy 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.

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. 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 experiencing Active Citizenship. 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. 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. Accessibility is also often considered in terms of physical access e.g. to buildings but the issue of accessibility of information is less commonly identified and dealt with.

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. 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 conclusion, there has been considerable policy 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. Even in countries where the process of closing the older hospitals has completed, a trend towards re-institutionalisation has been reported. 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.

2.2 The situation of people with disabilities from research - living situation, support and community participation

The aim of Work Package 6 was also to explore how societal changes affect the everyday life and living conditions of men and women with disabilities in Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK. Transitions from institutions to community living in Europe were specifically explored in task 6.2 where qualitative techniques were used to investigate the lives of disabled people over time with particular focus on community living and Active Citizenship. Deliverable 6.2 reported on data from 116 people across the nine countries. The section below mostly draws on that analysis but also includes some further analysis drawing on 202 interviews.

Some key patterns have emerged. Looking at current living situation the majority of people were living in their own home, owned or rented either on their own or with their partner and/or children. There were however some interesting differences between groups and countries. For example, those in Serbia and Italy more often lived with their parents or siblings and this was not just for the younger cohort. In Germany and Switzerland more people lived in larger settings provided by NGOs or in flats attached to larger settings. This type of setting was most common for those with intellectual disabilities.

The majority of the sample felt that they had full choice over where they currently lived, however those with intellectual disabilities were least likely to report choice over where they lived and whom they lived with. Those in the older cohorts most often reported full choice but this is likely to reflect the fact that many of those in the younger cohort were still living with their family. The report 6.2 also explored people’s experience in terms of institutionalisation and segregated or special accommodation settings. Those who had experienced institutional provision were more likely to be those born in the 1950s and those with intellectual disabilities, whilst those who had been to special boarding schools tended to be those with visual impairments.

Thirdly, the report explored the support people received related to their disability, in particular the support from social care or social services. In most countries the majority of people received some form of financial support but with enormous variation in the nature and amount of that support. Higher levels of support were most frequently reported for those with mobility difficulties. In Italy and Serbia people were more likely to only receive support from their family. Both paid staff support and support from families was reported in the Czech Republic, Germany, Ireland, and UK. Fewer people with intellectual disability reported choice over the type of support they receive, or who supports them.

Additional analysis of the larger sample of 202 people found that over 40% of people interviewed had had a personal relationship at least once in their life, with just under one third currently being in a relationship. Those with intellectual disabilities were again less likely to have had a relationship although there were some exceptions to this.

Almost half of those interviewed (n=202) reported having experienced difficulties with accessing the community in some way. A number of consistent themes emerged from the interviews. The first reoccurring issue impacting on community participation was difficulties with physical accessibility of community facilities and also difficulties with transport. The second issue raised was that of the attitudes of other people in the community – many people had had experiences of bullying and discrimination, some at school, some more generally in the community and some specifically at work. Some people talked about the fear of telling others about their condition because of the stigma associated with mental health conditions, others talked about having to fight to be allowed to get married, have children etc. Related to this was the issue of lack of accommodation provided at school and at work to allow people to fully participate.

The third issue met by those interviewed was lack of support or flexibility in the support they did have to allow them to use it to access activities in the community, to travel/attend work commitments in other countries etc. Some people also expressed a lack of support to understand the system of funding and support. Some people also raised issues such as lack of disposable income to allow them to do things in the community and also lack of friends, or lack of energy once they have been to work. A very small number of people, mainly those with intellectual disability, raised the issue of having restrictions on when they could go out placed on them by staff where they live.

When asked about what was needed to increase the inclusion of people with disabilities in society as active citizens, not everyone was able to give a response, but those that did generally focused on two things that were needed – 1) increased accessibility of all community facilities and transport and 2) a change in attitudes/more awareness in the general public about disability.

A preliminary analysis of the trajectories followed by people with disabilities in the nine countries was reported. Three clear patterns in trajectories emerged. Some people had experienced completely mainstream trajectories such as in education, employment, place of living and family situation. However, others mainly those with intellectual disabilities, had experienced "special" trajectories. A more mixed trajectory was more common for those with psychosocial disabilities some of whom had been in institutional provision for treatment and for those with visual impairments, many of whom had been to special boarding schools and or followed career paths specific to those with visual impairments (telephonist, typist, piano tuner etc.), as also reported in Deliverable D5.2.

Finally, analysis of the interview data for all 202 participants revealed that almost one third of those interviewed had worked (either in a paid or in a voluntary capacity) in a disabled people's organisation at some point in their lives, many of them still being active in these roles.

Limitations

This final finding is very likely to be an artefact of the recruitment strategy, which included approaching DPOs to help find people who might be willing to be interviewed. As such this introduces a bias into the study that it is important to acknowledge – the people included in the interviews were likely to be more able and more resourceful (in terms of personal resources such as education, confidence, experience, persistence as well as in terms of financial resources), than the average person with each type of disability. However, given the difficulties and at times negative experiences of fully participating in society reported by this group of people, we can be confident that the issues reported here will if anything be worse for those who are less able and less resourceful. This is particularly an issue for those with intellectual disabilities.

The other limitation here is that only those currently living in the community, with the majority living in their own homes, were included in the interviews. However, given the lack of choice and control over their lives and their support reported by many people, it can also be assumed that this will be even more the case for those who are in institutional settings or those who are under full guardianship. This is supported by the interviews with those with intellectual disability, who were more likely to live in some form of group setting, with staff support to the group and with restrictions on when they could leave the house, how they could spend their money etc.

So whilst we cannot argue that the sample interviewed here is, by any means, representative of all people with disabilities in each country, we can be relatively confident that the picture gained here is likely to be the best picture and that many people with disabilities will currently be experiencing less Active Citizenship than found for this sample. On a more positive note, this study did find that some people, including a small number of those with intellectual disabilities, were living very inclusive lives in their community, illustrating that it is possible for this to happen, when the right support is provided.

2.3 The views and experiences of expert informants

The basic methodology for the interviews with the expert informants was briefly outlined in the introduction. Reports from each interview were prepared in English and thirty-six of these interviews (4 from each of the 9 countries) were analysed in detail for the current deliverable. In particular, we focused on the interviews where people were able to comment on community living aspects specifically but ensured information on all disability groups was covered. Of those for whom data on characteristics were available: 50% were male; 61% were from DPO or NGOs, with the rest from the public sector; 65% worked at a national level.

The table in Annex 1 provides further detail about the positions and expertise of the informants. However, some details regarding people's positions have been changed in order to protect participants' identity.

The reports analysed varied in terms of length and detail provided. In some cases, they were written in the first person, as a translated transcript of interview and in others, they were written as the interviewers' account of the interview. However, both of these were in enough detail to allow the interviews to be coded for the following topics and initial themes:

- Current situation of people with disabilities
    - Living Situation
    - Choice
    - Support available
    - Variation by disability group
    - Variation by geographical location
- Changes in situation over time
    - Positive changes
    - Negative changes
- Barriers to the development of community living
- Facilitators of the development of community living
- What is needed for successful development of community living in this country?

Under each of these topics and themes, sub-themes were then identified. Three members of the research team read and coded the reports and all the themes and sub themes were then recorded in a word document, indicating which expert informant (e.g. NO1 – Norwegian informant 1) contributed to each theme. Any additional points that did not fit into one of the initial themes were also recorded along with quotations that might be useful for illustrating key points. The second author then checked all the sub-themes identified and collated them for presentation in the findings below. In some cases, a number of subthemes could be collated into a larger theme. For the topics where most information was available (i.e. barriers and facilitators) the themes and subthemes were summarised diagrammatically as can be seen in Annex 2 and 3. These diagrams also give an indication of which themes were identified in each country. It is important to note that if an issue was mentioned by even one expert within a country, it was included. We have not identified which interviewers made which points but rather we have collated the main findings from across the interviews. Interestingly, contradictory reports between experts within each country were not found, although of course opinions and perspectives on the situation did vary. In the sections below, we draw together the key findings from the expert informant interviews in order to complement the interviews with people with disabilities themselves and the review of literature and other documentation, in order to inform the recommendations. Any quotations provided are for illustrative purposes only.

2.3.1 Current situation of people with disabilities

> *'To what extent a person with disabilities may ... influence and decide about their life, and make their own choices and how their life trajectory will look like, I think, always depends on the type the disability and how much the person is affected'(CZ)*

One of the key themes that emerged from the interviews with expert informants was that there existed differences between different disability groups. In almost all countries community living was more thoroughly developed for those with mobility difficulties and those with visual impairments and was least developed for those intellectual disabilities, especially those with the most complex needs. For this group of people, the only option in most cases if people are not able to live with their families, is institutional or at least residential care settings – in some countries such as Italy, Germany, Switzerland and Serbia these can be larger hospital-like settings or larger group homes. In Ireland, options range small group homes through to larger residential settings and campuses. In others such as Norway, these are likely to be group homes (small flats co-located with other flats with staff support available up to 24 hours a day). Recent trends in Norway have seen these settings increase in size from less than 7 people to 10.

In most countries people with psychosocial disabilities were considered to receive the poorest support. However, in Italy the mental health services were reformed first and so services are generally better for those with psycho-social disabilities than in other countries.

There was also a situation of double jeopardy described in a number of countries – for example, older adults with disabilities and women appeared to achieve lower levels of participation and in some cases poorer services. Social exclusion was often made worse by poverty and many people with disabilities were reported as living in poverty. Finally, the issue of a "postcode lottery" was raised in a number of countries – i.e. where you lived as a person with disability dictated the support you received. This was raised both a local and municipality level but with one expert also talking about the differences between countries within Europe.

In some countries such as Germany, the overall picture that experts provided was still one of segregation for those with more complex needs – segregated education, segregated employment and segregated living. Even those living in the community were identified as leading isolated lives with little participation in community life – in Sweden, Czech Republic and Ireland.

Personal budgets or personal assistance existed in one form or another in all countries, but with enormous variation as to what that looked like, who was eligible and what the budget could be used for. In some countries, for example Switzerland, personal budgets were not available for people with intellectual disabilities. Lack of flexibility (for a variety of reasons but in particular lack of funding) within the system to allow real choice was a theme that was identified across all countries.

> *"I've certainly heard stories of people in their 30s; someone comes to put them to bed at four o'clock in the afternoon. Because that is the only time that the service provider can actually do it....."(UK)*

An issue that was identified in a number of countries was the issue of guardianship – many people, in particular those with intellectual disabilities, were under guardianship and persuading people that these people should have a say in their lives has been very difficult (e.g. in Ireland). There was a general theme that the voices of this group of people with more complex needs are often missing from the debate in most countries.

> *'Most people with physical and sensory disabilities live in the community; A lot of physical and sensory disabilities arrive later in life whereas people with intellectual disabilities have it from birth which can impact on different groups' access to family and social supports and thus their ability to live in the community. Very few people with intellectual disabilities marry or have long-term relationships or children. People with intellectual disabilities live with their parents into their late thirties typically and then move into residential services with three to four strangers. They go from special schools to disability day services to residential services. When their parents die, they don't have children, grandchildren or as much extended family around them as social support and end up in residential services. (IE)'*

Finally, the issue of geographical variation within countries was raised. For example, in the UK, implementation of the CRPD is further behind in Northern Ireland than in England, Wales and Scotland. In Switzerland services varied from canton to canton; similarly in Germany from land to land. There were also geographical differences noted in other countries too – between municipalities in Norway and Sweden or between local authorities in England. In most countries, it was possible to be able to get one type of support in one locality but not in another. One interviewee also commented on the differences between different EU member states.

> *'Participation of the family in social life and of people with disabilities in family life is a matter of fact in the French and Italian part, but not in the German part where family members with disabilities are often cared for outside the family home. These cultural differences entail a different understanding of self-help. In the non-German parts it is more important to come together AS people with*

> *disabilities for a glass of wine than to fight for inclusion because this fight is not as important since one is always taken along by the family" (CH)*

2.3.2 Changes over time related to community living

As highlighted in the previous section, there remains a very mixed picture related to the implementation of community living in many of the nine countries involved, especially for those with intellectual disabilities. In some countries, there were some more negative changes highlighted including, for example, a trend towards re-institutionalisation or at least the collective organisation of support and services, rather than individually focused supports (in the Scandinavian countries), a weakening in the Disabled Peoples Organisations in some countries such as Sweden, and a move towards a more individualistic and less citizen focused society (such as in Sweden). Reduced funding (in some cases due to austerity measures as a result of the financial crisis) and less flexibility in what can be claimed was identified as a negative change in Sweden, UK, Serbia and Germany. Despite increased recognition of disability and calls for inclusion funding for education and social care has not increased.

Other changes that were seen to have a more negative impact have included the marketization of support services and the resulting fragmentation of the service system. Also leading to the fragmentation of services has been then devolvement of responsibility for some services (but not necessarily all) to lower levels of government – municipality or local. However, expert informants also identified some important positive changes in recent years. The most commonly identified change was the development of good policy – policy aligned with the CRPD. Whilst not all policy in all countries was aligned – the most common exception was policy related to guardianship and supported decision making (and thus Article 12) – policy, national plans and strategies that were supportive of community living had developed over the past 10 years in the Czech Republic, Norway, Italy, Ireland and Germany). Development of personal budgets and personal assistance schemes, even if not yet fully implemented, were also seen as positive.

Whilst reduction of the funding and influence of DPOs was noted for some countries and seen as a negative change, in other countries, such as Ireland, DPOs and Independent living movements have been growing and have been very important in bringing about the changes currently happening in terms of policy and systems. There have been changes in the number of people in institutions and the number of those living independently.

There were also noted positive changes in attitudes and awareness - People themselves were, in some countries, more aware of their rights and of the possibilities of personal budget schemes and were more likely to be seeking "support" rather than "services". There has been a more general increase in awareness of human rights and a more acceptance that self-determination and self-advocacy are important paradigms and that people with disabilities should also be able to live individual lives, included in society. Change in societal attitudes towards people with disabilities was primarily attributed to people with disabilities being more visible in society due to a more accessible society and the fact that more people are more likely to be in inclusive education, less likely to be segregated in institutions, more likely to be in open employment. As noted in the earlier section, this was more likely to be true for those with physical and sensory disabilities than those with intellectual disabilities.

2.3.3 Barriers to development of community living

Seven clusters of themes related to barriers were identified. These were:

1. Policy and politics
2. Funding availability and systems
3. Co-ordination and organisation across levels of government and other agencies
4. Attitudes and awareness
5. Availability and flexibility of services and support in the community
6. Influence of people with disabilities and their representatives
7. Perverse incentives for the maintenance of institutional provision, contractions in the system and issues of definition and conceptualisation

Annex 1 shows the mapping of the themes within each of these clusters and the countries to which each theme applied. We will present in summary form the key findings for each cluster below.

Policy and politics

There were a number of themes that related to the presence and nature of policies to promote community living. In some countries there was very little policy or the policy that existed was perceived to have the wrong focus or as not helpful in promoting community living: So for example the following weaknesses were noted by interviewees: good accessibility policy was lacking in Sweden; In Norway it was reported that policy was open to interpretation and in general still focused primarily on a more medical model of disability. Likewise in Ireland the model in policy was still primarily the medical model. In many countries Guardianship laws still existed which were considered as problematic for people having real choice and control. In Italy, Serbia and Switzerland, the policy that existed was not helpful in promoting community living for all. However, even where good policy existed, it was reported that there were issues of implementation in Serbia, Czech Republic, Italy and Ireland – either implementation at local level, in practice or for all disability groups.

For some countries the political systems themselves were seen as barriers at times – for example in Italy the lack of political stability was an issue; In Italy and Serbia, the controlling nature of government was identified as problematic; and even in the UK, the way the Coalition government responded to crises was also seen as an issue.

A lack of government focus or priority on disability issues was identified as a barrier in the Czech Republic, Norway, Italy and Germany. In addition, in Norway, the almost exclusive focus on promoting personal budgets to the exclusion of all other options for services was viewed as problematic especially for those with more complex needs.

Finally, in Germany and Ireland, there was an explicit barrier identified in the over-riding concern of government (at different levels) being costs or expenditure. However this theme was also implicit in what was said for some other countries too in terms of cost cutting, cost shunting and rationing of services seen in the UK and Sweden too. This is explored a little more in some of the following sections.

Funding availability and funding systems

In almost all countries, (apart from the Czech Republic and Serbia), most interviewees identified the issue of a lack of spending on disability due to a range of reasons, including austerity measures as a result of the financial crisis or in some cases just a general reduction in spending over time. The lack of funding applied both directly in terms of funding for support and housing but also in terms of funding for schemes that would help people be more independent and therefore need less funding overall – for example, in the Czech Republic it was noted that the funding system needed to help implement the policy still didn't really exist and in general there was a lack of funding to support families to look after people at home for longer should they wish to do so and that services such as self-help groups for those with psychosocial disabilities were not seen as eligible for funding.

Finally, there were a number of issues around the use of funds in addition to the limited funding available in Italy: Firstly, it was reported that money was often spent inefficiently or on the wrong things – i.e. not what people needed or wanted. Secondly, there is a lack of leadership as to how money should be spent and thirdly, misuse of EU structural funds was noted. Although primarily raised by Italian interviewees, it is likely that these issues may apply in other countries as various perverse financial incentives were reported (see later section) and more generally, we know that in other countries the misuse of structural funds has occurred.

Co-ordination and organisation across levels of government and other agencies

There were three core barriers identified that affected co-ordination and consistency within the system. In many countries there was geographical fragmentation that affected the services people received – In Germany, the Federal system was seen as an issue, in the UK the "postcode lottery" was identified and in Switzerland the differences between Cantons was also identified as problematic for the consistency of support available to people. In six of the nine countries, interviewees identified a lack of co-ordination between different levels of government as a barrier to change happening more consistently and widespread and sometimes this was identified as a way of cost shunting from one department or level of government to another. Finally, interviewees in Sweden, Ireland and Germany identified compartmentalisation of the system as a barrier along with lack of co-ordination and co-operation between service providers, agencies and across sectors (e.g. health, social care, education, transport etc.).

Attitudes and awareness

The fourth cluster of themes was around issues of attitudes towards people with disabilities as well as awareness of issues facing people with disabilities. A number of the themes that emerged here were interlinked. Experts in Sweden, Ireland and Italy specifically mentioned that fact that society was no more individualistic and less concerned about others or at least there was less solidarity against oppression than there had been in the past. In the Czech Republic prejudice was still an issue and in the UK the issue of discrimination and victimisation was raised. Stigma was also raised as an issue in UK, Germany and Sweden, especially with regard to people with mental health conditions and this was specifically linked to a lack of awareness around mental health conditions in Germany.

Lack of knowledge and awareness on the part of decision makers (i.e. those deciding on care packages) was raised as a barrier in Sweden, as was a lack of awareness of the rights of people with disabilities by people with disabilities themselves and their families. The latter was also seen as a barrier to change in Italy and Germany.

There was also the issue that some people still believed that institutions were needed and acceptable as a form of provision. However, this was at times somewhat confused by differing definitions of an institution. But in at least two countries (Czech Republic and Switzerland) it was felt that some people needed institutions and that indeed some people, including those with physical disabilities, would choose to live in institutions and that having institutions was necessary to give people a full range of choices. These attitudes also applied to some of the interviewees, which was concerning given their leading role in advocating for or delivering community living. Although the issue was only raised specifically in two countries, it is highly likely that in other countries there are still beliefs that people with more severe disabilities need to be in institutional services as they are still being placed there.

Linked to this issue, was a specific issue raised in Sweden but likely to apply elsewhere and that was the current debate around what should happen to sheltered workshops. This is a segregated form of employment with limited pay, which does not fit into CRPD vision of employment, nor is it consistent with the vision of community living. However, it does provide people with daytime activity and gives people the opportunity to meet other people with disabilities. In Sweden, these are accessed by those with physical and sensory disabilities as well as those with mental health needs.

Finally, two other issues were raised – one related specifically to Norway and that was the lack of criticism or even discussion related to disability issues in the media. Unlike in other countries such as the UK, where scandals were common and much debated, in Norway there appeared little discussion about the situation of people with disabilities.

The second one was a more far reaching issue and that was the fact that in particular in Ireland and Switzerland, the idea that disability equated to charity was deep rooted. Caring for people with disabilities was seen as the primary aim of services and support mechanisms, rather than empowering and enabling people.

Availability and flexibility of services and support in the community

This was one of the bigger clusters, with 9 themes. The only country not represented within this cluster was Serbia where this was not raised as an issue – possibly because services in the community were relatively rare as this quote from one of the informants from Serbia illustrates: *‘Everything is still a matter of who knows who, and of individual efforts. There is no systemic support or conditions’.*

Firstly, in Switzerland, Germany and Italy, the issue of the bureaucracy involved in obtaining and then managing a person budget or personal assistance made it difficult for many people with disabilities and sometimes put them off applying. The fact that people had to be employers for personal assistants was a particular issue raised. There was also discrimination against people with intellectual disability and psychosocial disabilities.

> *‘Another problem is the discrimination of people with psychosocial problems and with cognitive impairments since the eligibility for the assistance budget depends on the eligibility for the so-called Hilflosenentschädigung (“compensation for the helpless”), for which restrictions exist for people with psychosocial problems and cognitive impairments. This is essentially scandalous and, in the interviewee’s view, illegal, but no one fights back. The organizations catering specifically for these groups do not resist. Because a study has found, they do not have a stake in it as they would not receive the money themselves. Instead, the money goes to their clients who, therefore, become less dependent on the organizations. The interviewee knows few people with psychosocial problems who have applied for the assistance budget. (Name of Organisation) has assisted three of them, two were successful. The impact of the budget on life quality is even greater for them than for other people with disabilities, but in both cases, it took two years of fighting to get the application accepted. Only few people are able to overcome the barriers on the way to receiving the assistance budget” (CH)’*

Secondly, in Switzerland, Czech Republic, Italy and Germany the fact that institutional services (larger scale residential care) were still being built or at the very least still being used for new people entering the service system was seen as a barrier by the experts from those countries. The issue of how to support older people with disabilities compounded the tendency for people to believe that institutions were still needed for this group in the Czech Republic. The issue of assistance only being given for personal and health care and not for social assistance was raised by Italian experts.

Even when the main form of support was community based and included social assistance, there were still issues identified particularly around flexibility of support. In five of the nine countries (NO, CZ, SE, IT and IE), experts raised the issue of the inflexibility of support funded – money was given to people but not necessarily for the things they wanted or needed. Two additional barriers to full community living were raised by experts in Sweden - firstly the issue of lack of choice over *when* carers come in to provide support and well as *who* supports them was raised. Secondly, there appeared to be little recognition that the needs of people might differ over time and as such support might need to change – in both directions. This was particularly an issue for those with mental health conditions.

Finally, there were barriers identified around accessibility and availability of assistive technology. In Norway, Ireland, Italy and Sweden, issues of accessibility of the community in general were noted as problematic. In Ireland, one barrier identified to supporting people to leave institutions was the lack of accessible homes available. In the Czech Republic, there was a lack of funding for assistive technology.

Influence of people with disabilities and their representatives

The penultimate cluster of themes included three core themes (and one sub theme). For all countries the lack of involvement of people with disabilities (both directly and through disabled people's organisations) in the political arena emerged. In the UK, Serbia and Ireland, it was identified that influence was limited to the "elite" – i.e. powerful, well-resourced and well-known individuals. In Switzerland, it was noted that politicians do not acknowledge the need to involved people with disabilities – they do not necessarily subscribe to the "nothing about us without us" maxim. Finally, in Norway, Italy and Sweden, the fragmentation of disabled people's organisations was identified as an issue – they were not working together to put forward a united front and as such were weaker than they needed to be to influence government and local decision makers.

Perverse incentives for the maintenance of institutional provision, contradictions in the system and issues of definition and conceptualisation

The final cluster of themes brings together a number of issues. Firstly there were still financial incentives for institutional services in some countries - for example in Germany and Switzerland it was identified that local levels of government were motivated to keep institutions open as cheaper for them than community based services. In Ireland, it was identified that psychiatric hospitals received funding on a per capita basis so there was no incentive to close the institutions. Even if one person moved on, someone else would be moved into the bed.

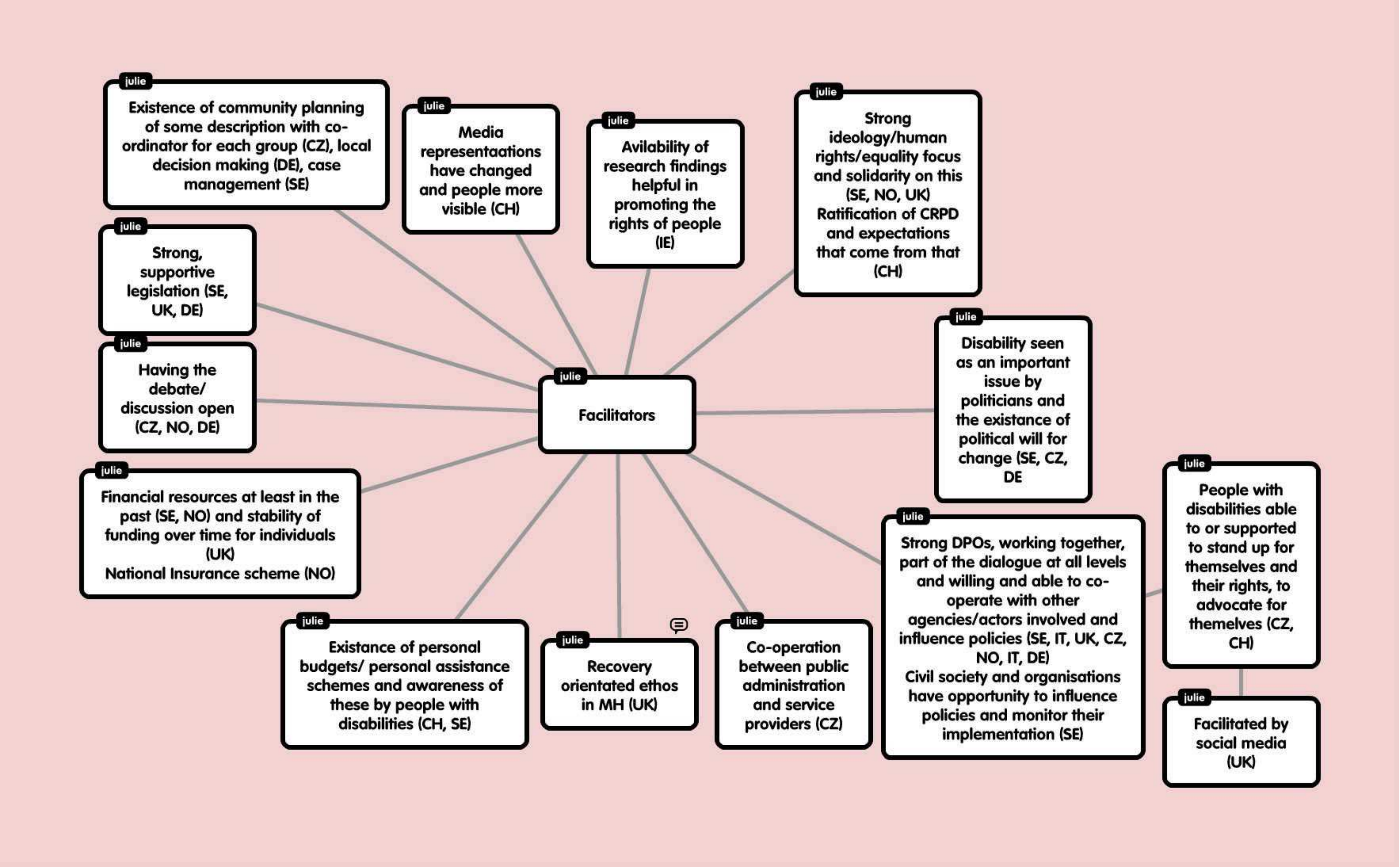
In terms of definitions and conceptualisation, it was recognised that some countries had mistranslated key terms from the UN Convention – for example in Germany the word "integration" is used rather than the word "inclusion". Although not identified as a barrier by any one expert there was an implicit theme that was identified by the research team and that was the substantial variation in the definition of what constitutes community living and what was meant by institution.

Finally, there was an issue about inherent attitudes or ways of working within the systems. In many countries, and raised in particular in Ireland, the systems still fostered dependency rather than independence. This is related to the barrier raised earlier around the deep-rooted attitude in society that disability = charity required. In the Czech Republic and Serbia it was explicitly mentioned that it was "who you are and who you know" that determined the services that you received – so individual resources are what makes a difference to your own situation. This issue was also implicit for other countries too – those who were able to speak up for themselves more easily tended to have better experiences. Finally, the fact that there was an increase (Italy) or at least maintenance (Germany) of special/segregated educational provision was seen as an important barrier. Again although specifically raised in these two countries, this was still likely to be an issue in other countries where a special school system still exists.

2.3.4 Facilitators and what is needed for success

As one might imagine, the facilitators identified by experts in each country were in general the opposite of the barriers already outlined above. In addition, what was needed for success was also generally related directly to the barriers identified. Figure 1 below presents the key facilitators that were identified by the expert informants as having been important in bringing about change in favour of community living.

Figure 1: Themes arising under the topic of facilitating factors for Active Citizenship through community living



The twelve themes and two sub themes identified as facilitators of community living and Active Citizenship were closely replicated in the analysis of what experts felt was needed for future success in their countries. The key suggestions across all thirty-six interviews are summarised below:

1. A more holistic or comprehensive view of people and of disability support – people should not have to manage contact with multiple departments or agencies to get their needs met. This is partly associated with a needed change in attitudes from a primarily medical model of disability and support to a system that includes social aspects and that starts from a position of equality (and a focus on anti-discrimination).
2. Better co-ordination between different levels of government and the involvement of people with disabilities in decision and policymaking at all levels. In some cases this requires changes in government structures. The key issue here is to stop cost shunting and provide a more consistent and holistic person-centred approach.
3. Need individual person-centred approach – planning and support across life and less focus on "services" per se.
4. Need to encourage and if necessary support people with disabilities to act in more influential positions.
5. Increased awareness (in government and more widely) about disability issues and what good practices might look like, especially for those with higher support needs.
6. More money for services with stability over time, developing alternative forms of funding to meet people's needs more efficiently and effectively. Personal budgets and personal assistance were seen as a key route to meeting people's needs in the way that works best for them.
7. Those with mental health needs require a more flexible system of funding and support so that they can have helped in the periods of time when they are in crisis but have some ongoing (light touch) support (e.g. self-help groups, regular consulting/advocacy) when they are well.
8. Those in positions of leadership need to have the room/opportunity/mandate to lead and make decisions BUT these must be in line with the CRPD. Awareness about the CRPD needs to be raised for stakeholders at lower levels of governance.
9. DPOs and other minority organisations need to unite and strengthen their political voice and bring together a unified campaign for all people with disabilities.
10. Need "real" inclusive education to bring about change in societal attitudes, awareness and ultimately culture.
11. Need to strengthen the European Human Rights Commission so that people can fight for their rights.
12. EU need to lead on ensuring money they give is spent compatibly with the CRPD and that there is consistency across states.
13. Focus is needed on recovery, rehabilitation and supporting people to have a better life.

14. Inclusion needs to be seen as a goal in itself and not as a way of minimising costs.
15. Need ongoing research to show how well things are implemented and what else is needed.

2.3.5 Conclusions from expert informant interviews

These interviews provided some very rich data that were consistent with findings from the analysis of policy, official statistics and previous research and with the findings from the interviews with people with disabilities themselves. There are substantial numbers of people still living in institutional settings and there remains much confusion, perhaps sometimes created intentionally by mistranslation of the UN Convention and the use of misleading terminology, as to what counts as an institution and what is community living. Lack of awareness and unhelpful attitudes was a key theme as was co-ordination towards the common goal of inclusion. The UN Convention was generally seen as useful but not everyone interviewed was aware of what it included and what it meant for their country. Although there were some themes that applied more to countries that were just beginning the process of deinstitutionalisation, one of the key findings here is that many of the barriers and the facilitators were the same across different countries of different welfare state systems and at different stages in the development of community living settings. This is consistent with the DECLOC report recommendations (Mansell et al., 2007)[4] which pulled together a number of common elements that needed to be present in order for community living for all people with disabilities to become a reality.

3. Summary and Recommendations

3.1 Summary

The aim of the task 6.3 was to formulate recommendations to support deinstitutionalisation and to promote, and sustain, the development of community living for all people with disabilities.

The United Nations Convention on the 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. In addition, living in the community and not in congregative settings such in institutions is a key pre-requisite for Active Citizenship. Mansell, Beadle-Brown, *et al* (2010)[5] noted that institutions were originally defined in general as large

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

[5] Mansell, J. and Beadle-Brown, J. (2010) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of

congregated settings that function on a medical model and institutional practices as marked by social distance, rigidity of routine, block treatment and depersonalisation. More recent definitions included lack of choice and control as an important facet of institutional care. As reported in Deliverable 6.1 the countries studied appear to be at different stages of deinstitutionalisation. In some countries such as Norway, Sweden and the UK, the closure of institutions has been mainly completed but some evidence of re-institutionalisation was noted. 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 less severe disabilities have the opportunity to live in the community. Although the lack of data is an issue, the overall picture is not very encouraging with little apparent change in the situation for those countries included in previous research such as the DECLOC study (Mansell et al. 2007). However, in all countries there were some good examples of community living even if small-scale and limited to some particular groups of people with disabilities. Deliverable 6.1 identified the importance of the quality of the support people receive to promote full Active Citizenship in the form of participation around the home and in the community – in household, leisure, social and work related opportunities. This is particularly important for those with the most severe and complex needs. However, in order to do this staff need to have both the right attitudes and the skills to enable and empower people (Mansell and Beadle-Brown, 2012[6])

The previous point leads on to one of the key findings from Work Package 6 on community living and that relates to the differences that emerged between different disability groups. In almost all countries community living was more thoroughly developed for those with mobility difficulties and those with visual impairments and was least developed for those with intellectual disabilities, especially those with the most complex needs. Secondly, people with psychosocial disabilities were often considered to receive the poorest support for participation in community life. Social exclusion was frequently made worse by poverty. Many people with disabilities were reported as living in poverty. Some forms of personal budgets or personal assistance existed in all countries, but with variation in terms of the forms, eligibility and what they could be used for.

With regards to the influence of people with disabilities, the voices of people with more complex needs are often missing from the debate. The lack of involvement and influence of people with disabilities in the political arena was also reported in most countries.

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the International Association for the Scientific Study of Intellectual Disabilities, *Journal of Intellectual Disability Research*, 54, 2, 104–112.

[6] Mansell, J. and Beadle-Brown, J. (2012) *Active support: enabling and empowering people with intellectual disabilities.* London: Jessica Kingsley Publishers. ISBN-10: 1849051119.

In addition to the issue of re-institutionalisation already mentioned above, expert informants in some countries identified the marketization of support services and the resulting fragmentation of the service system as an important negative change that resulted in lack of co-ordination of services. Some important positive changes in recent years were also identified, the most common being the development of good policy aligned with the CRPD. However, there were still some barriers that arose from lack of helpful policy, misinterpretation of policy or from the lack of implementation of policy and procedures that did exist. In addition, there was the lack of awareness of the CRPD found at lower levels of government, which could also be a barrier to implementation. Although there had been some development in terms of legislation related to guardianship and decision-making, guardianship laws were still seen as problematic for people having real choice and control. Development of personal budgets and personal assistance schemes, even if not yet fully implemented, were also seen as positive. There has been a more general increase in awareness of human rights and more acceptances of self-determination and self-advocacy. Change in societal attitudes towards people with disabilities was primarily attributed to people with disabilities being more visible in society due to a more accessible society in general, including inclusive education and open employment. The over-riding concern of government (at different levels) being focused on costs or expenditure was also identified as a barrier.

Three core barriers were identified that affected co-ordination and consistency within the system: geographical fragmentation that affected the services people received, lack of co-ordination between different levels of government as a barrier to change, compartmentalisation of the system as a barrier along with lack of co-ordination and co-operation between service providers, agencies and across sectors (e.g. health, social care, education, transport etc.).

Prejudice and stigma towards people with disabilities and lack of knowledge and awareness of disability issues at different levels, were also identified as barriers to full participation in the community. There was some indication that there still existed the belief that people with disability, and particularly those with more severe disabilities, need to be in institutional services and this was confirmed by the practice of the continued development of new institutions or at the very least institutions still being used for new people entering the service system was mentioned as a barrier.

Where support for community living, and in particular personal budgets, existed, the issue raised was primarily around the level of funding and the flexibility in how money could be used, not being enough to allow people to real choice and full participation. Related to this there appeared to be little recognition of changing needs of people over time and the fact that support might need to change. Bureaucracy associated with obtaining and then managing a personal budget or personal assistance was also noted as making it difficult for many people with disabilities to access this type of support.

Finally, several facilitators of community living and Active Citizenship were identified. These included: having a more holistic or comprehensive view of people and of disability support; better co-ordination between different levels of government; co-operation between DPOs to create a unified approach to strength the voice of people with disabilities; the involvement of people with disabilities in decision and policy making at all levels; having an individualised, person-centred approach; encouraging and if necessary supporting people with disabilities to act in more influential positions; increased awareness about disability issues and what good practices might look like, especially for those with higher support needs; and developing alternative forms of funding to meet people's needs more efficiently and effectively. It was also suggested that the EU need to lead on ensuring that the money they give is spent compatibly with the UNCRPD and that there is consistency across member states. As one expert informant noted, inclusion has to be seen as a goal, not as a way of minimising costs.

3.2 Recommendations

These recommendations are based on all the findings from Work Package 6 – on the suggestions by expert informants and by people with disabilities themselves, as well as on the recommendations of previous research and development work, reviewed in Deliverable 6.1, which remain valid.

At European level

1. Establish a minimum dataset related to living situation, which all States are expected to provide data for in a format that can be compared across countries and which allows the monitoring of where people are living over time and what support is available to help them to live and participate in their community as active citizens. It remains very difficult to obtain reliable data about the living situation of people with disabilities. The official statistics that exist are plagued with limitations and are rarely comparable from place to place which makes it difficult for people to have choice around where to live within Europe. Implementation reports for the UNCRPD do not require data in any particular format and as such are therefore very difficult to compare. Currently Ireland is still the only country that has a national database for those with physical and sensory disabilities and those with intellectual disabilities. While far from perfect, these databases at least allow the monitoring where people live and the level of support they receive which allows trends over time to be explored. Establishment of such a database, that also includes children, can be initially time consuming and require some resources but it can greatly improve service planning and supports monitoring of the UN convention across time. However varying definitions of service types, community living etc. are an issue across different countries - as such, there needs to be a common set of definitions for different types of services/supports, irrespective of what they are called in each national language, should be the same for data purposes. Some suggestions for what categories might be useful to use in such a dataset can be found in Annex 2. Having such data available would also help people with disabilities be an active citizen within Europe, and make the most of their freedom to move between countries as they would be able to find out whether the services that best meet their needs and preferences are available.

2. European Commission should continue to monitor how European funds are used and to set conditions on their use so that support developed for people with disabilities so that they have the chance of achieving Active Citizenship. We would suggest, from previous research based on those with the most severe needs, those with intellectual disabilities, that all new support options develop should fall within the first four categories in Annex 2 (i.e. in groups of less than 7 people, living in ordinary houses dispersed in the community, preferably with people they chose to live with and with support to access the opportunities available to them in the community). This is based on the assumption that not all countries will be able develop a system of personal budgets in the immediate future and as such it will be necessary for people to live in small shared accommodation that might be rented for them by NGOs, as many people with disabilities will not have any disposable income available to pay rent themselves. Of course, as noted earlier, just ensuring that people live in smaller dispersed housing in the community is not a guarantee of Active Citizenship and better quality of life but creates the right context, helps people to be seen in the right way by others and makes opportunities more easily available to people. For some people, in particular those with supportive family and friends, that might be enough to promote their participation in the community. However for others the quality of the support they receive will be critical and in particular their skills in person-centred support. ***The European Commission should ensure that requests for financial support include detailed accounts of how staff will be trained and supported to work in the enabling and empowering way needed to help people exercise Active Citizenship***.

At National government level

In most countries, policy already existing that allows community based services to be established. However, in some countries involved in this project further developments were needed in terms of useful policy. The power or importance of policy varies across countries.

3. National governments need to provide the right messages, definitions and leadership around disability issues and in particular around support and accommodation services to ensure consistency at different levels of government and across geographical locations. This would include support and initiation of awareness raising campaigns, working collaboratively with Disabled People’s Organisations. The best way to change attitudes towards people with disabilities is by ensuring that they are an active member of society – this means that they need to be visible within at least their local community, supported to participate in society, not just be present in it and helped to have a valued role and contribute to society – through work, volunteering, caring for and supporting others. As such all government policy and systems need to be consistent with the aim of promoting the full inclusion of all people with disabilities in society. This should include educational policy and accessibility and anti-discrimination policy. Interacting with people with disabilities in positive situations is what is most successful at changing attitudes towards people with disabilities.

4. It should be clear and transparent as to who holds primary responsibility for disability issues – this does not necessarily mean that one department or organisation needs to do everything related to disability but that someone has an overall view of disability policy and systems to ensure a comprehensive and holistic experience for those who need to access the system**.** This needs to be consistent over time and irrespective of which government is in power.

5. Governments need to ensure that funding systems are available, efficient and flexible so that people get the support they need. This might require establishing new sources of income and reorganising how money is currently allocated. If this is done in a person-centred way then it is likely to result in an overall balance in the costs and certainly in greater cost effectiveness (See Mansell et al., 2007), because some people will currently be receiving more support in restrictive settings than they need and a small amount of the right support at the right time may in the long run save money. Encouraging and supporting people to work and to be as independent as possible will in the end make them less reliant on the system for welfare benefits etc. This leaves more money in the system to allow those who need more support to live a good life in the community to get that support. It is important to remember some of the lessons from research in the UK - good support that enables and empowers people does not cost more than support that is based on dependency and disability – it is not about how many staff you have (once you have enough to meet people's basic needs and keep them safe) – but rather how staff think and work with people that is most important (Beadle-Brown et al. submitted). ***Ensuring that organisations that are registered to provide services are training and supporting their staff to work with person-centred and enabling approaches is important and national governments should ensure that this is reflected in registration and inspection or quality assurance systems.***

6. National governments need to monitor the implementation of policy on a regular basis – this could be encouraged on a consistent basis through the need to provide data for the national dataset to monitor progress towards community living for all people with disabilities.

7. In establishing deinstitutionalisation programmes, national governments need to ensure that they include all people with disabilities, not just those who are more able. This is extremely important for shaping up the expertise of community based services to support those with more complex needs and also for spreading the costs of transforming services across time.

8. National governments need to consult and involve people with disabilities and their representatives in any decisions that affect people with disabilities. This should not be limited to the "elite" but effort should be made to consult people more generally, through DPOs, user forums, media consultations etc.

At local government level

Most of the recommendations made at national level also apply at local government level.

9. In particular, local governments need to have a holistic and life course approach to disability and ensure a consistent and co-ordinated approach.

10. They need to work with local DPOs and consult people with disabilities in making local policies and when making decisions affecting people with disabilities.

11. The need to ensure a focus on all people with disabilities and not leave those with the most complex needs to the end of the process of deinstitutionalisation.

12. Local governments need to provide clear guidance and leadership to those providing accommodation and support to people with disabilities as to the nature of services that will be funded and what is expected of those services in terms of outcomes for those supported. This needs to be consistent with national guidance and with the UNCRPD. There needs to be flexibility within the system to allow individuals' needs to be met. Funding what might be considered "alternative" services that help people to keep well and independent can often be a much more efficient way to spend money – especially for those with mental health needs – for example self-help groups, regular therapy sessions, access to drop in support when needed, support to find a job and to negotiate reasonable accommodation to ensure success, support to access regular exercise. Encouraging people to work when they can and then be able to easily access support when they cannot due to illness or increased disability will in the long run be more likely to mean that people will try to find jobs and therefore contribute to the general economy and less likely to access more intensive services and higher level benefits. As for national governments, local governments must encourage service providers to support that enables and empowers people with disabilities to achieve Active Citizenship.

13. The systems for applying for support need to be made more transparent and support available to help people apply. This is important to make the system fair as without this only those who are fortunate enough to have the personal resources or have the support of a family member or advocate, can access support. As such those who need it most are often missing out on support. It is acknowledged that making the bureaucracy excessive might be an intentional strategy to reduce application but this is not in line with the UNCRPD.

Disabled People's organisations

14. DPOs should work collaboratively with each other and with other agencies as much as possible to help raise awareness about disability issues and the CRPD at all levels

15. They should work together to ensure that the voices of all people with disabilities are heard at local and national government levels and also by service providers designing services etc. It is important that campaigns should not just focus on what is going wrong but give solutions for how things could be done differently/better. As part of this DPOs will need to work with those providing services and where possible with supportive local governments to demonstrate that alternative models can be established within current budgets.

16. DPOs should work collaboratively with other agencies to ensure that people with disabilities themselves (and their families and carers) have access to information about their rights and the services available to them. They could also help people with disabilities, including those with more severe disabilities, advocate for themselves and tell their stories to those making decisions affecting the lives of people with disabilities.

Service providers/NGOs

17. All those who are providing accommodation and/or support services in any sector for people with disabilities need to be willing to work together with each other and with local government and NGOs to provide a holistic service for people with disabilities. This might mean that service providers working in close geographical proximity might need to share resources such as trainers and training programmes, professional input (psychology, speech and language therapy, OT etc.), office space or other facilities etc.

18. They need to be willing to find alternative ways of providing support that are consistent with national definitions of community-based services and the UNCRPD. Finding ways to respond flexibly to people's needs, increasing and decreasing support as needed, is important. This often means breaking with traditional methods and being creative, using volunteers, employing staff in different types of roles, using technology etc. In order to free up resources to provide support for someone to go to work or to attend the evening club they really want to join, it might be necessary to make savings elsewhere – but often this can be an opportunity for people to be more involved in their own lives – e.g. if people have access to a garden or allotment, they could be supported to grow, harvest and then eat or sell vegetables and fruit. This might be possible in small groups depending on the levels of need of the individuals involved – however, we know that skilled staff can support more than one person at a time in this type of activity. Not only might this save money on food but it also provides lots of opportunities for engagement in meaningful activity, for physical exercise as well as for contact with members of the general public and the opportunities to contribute to society more generally, by for example, sharing food with other people who might not have much to eat. Other examples are things like supporting small groups of people to look after local gardens, offer pet sitting services, clean windows etc. These also help people to develop new skills that enable them to find a job on the open market, thus further improving their financial situation and their role within society.

19. They need to consult with the people they support and their advocates to ensure they are meeting people's needs and providing a service that is working for people.

20. They need to ensure that they provide training and support to staff to work in a way that supports people to be active members of their community and to experience choice and control in their lives. This is important to ensure for all people with disabilities but requires additional skill when applied to those with the most severe disabilities. It requires a change in attitude as well as working practices for many of those currently employed in services. It requires staff to put the person or people they support at the centre of what they do, listen to them, support them to try things, have new experiences, and empower them to make decisions and take control of their life as much as possible. This is possible even for those with the most severe disabilities if staff have the skills to do so. In addition to having the skills to support people in this way, staff needs to be motivated to do so and this requires good leadership, clear expectations and appropriate contingencies from managers.

Annex 1: Table 1 Informant characteristics

Country	Gender	Sector	Level of governance	Current Position	Area of Expertise
Czech Rep._01	M	Public	National	Senior member of Governmental Board for People with Disabilities	Anti-discrimination policies
Czech Rep._02	M	NGO/DPO	Regional	Founder & Director of an NGO	Community based services, supported employment
Czech Rep._03	F	Public	Local	Senior official in Department of Social Services	Community planning
Czech Rep._04	M	NGO/DPO	National	Chairman of an NGO	Social rehabilitation, visual impairment
Germany_01	F	NGO/DPO	DNP	Director of a DPO	Persons with cognitive impairments
Germany_02	F	NGO/DPO	National/Intern.	Director – DPO	Persons with visual impairments; disability policies
Germany_03	DNP	Public	Local	Head of Dept. of social psychiatry within the local health authority	Psycho-social problems
Germany_04	DNP	NGO/DPO	National	DNP	Disability rights activism/self-presentation
Switzerland_01	DNP	NGO/DPO	National	Head of social policy department and vice president of NGO	Disability /general
Switzerland_02	M	NGO/DPO	Regional	DNP	People with psychosocial problems
Switzerland_03	M	NGO/DPO	Regional	Senior representative from Centre for Independent Living	Community Living, General
Switzerland_04	DNP	NGO/DPO	National/Intern.	Executive director - social issues and advocacy	Intellectual and developmental disability
Ireland_01	F	Public	Local	Access and Equality Office/Government	General/local government; EU policy
Ireland_02	M	Public	Local	Member of Direct Payment support network	Community inclusion/political activism
Ireland_03	F	Public	Local/regional	Public servant working in the disability area	Disability /general
Ireland_04	F	DNA	DNA	Community activist	Political participation
Norway_01	M	NGO/DPO	National	Special advisor on disability	Disability advocacy
Norway_02	F	Public	National	Senior Advisor, Ministry of Health and Care Services	Implementation of personal assistance

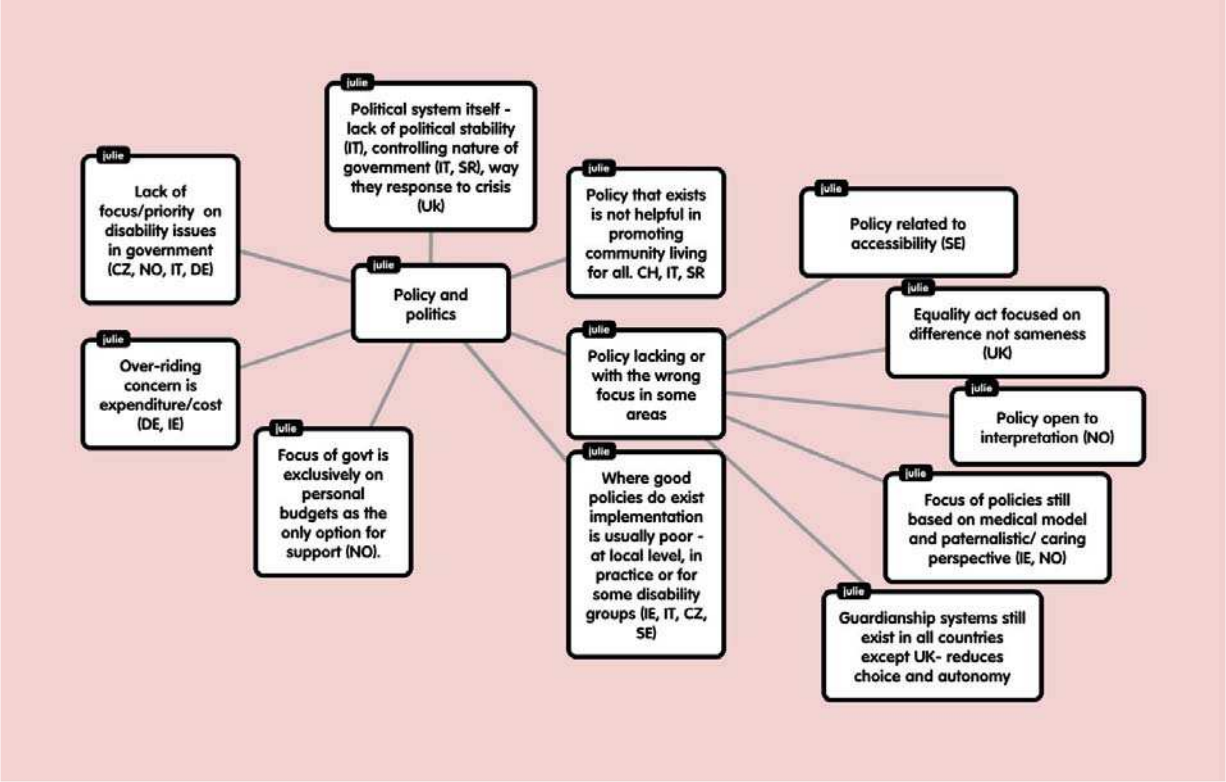
					scheme
Norway_03	F	NGO/DPO	National	Director of the organization for independent living	Disability policy, human rights
Norway_04	M	NGO/DPO	National	Vice-President	Disability policy
Sweden_01	F	NGO/DPO	National	Chairman of disability federation	Disability /general
Sweden_02	DNP	NGO/DPO	Local	Focus group with 4 managers service providers	Psychosocial disabilities
Sweden_03	DNP	NGO/DPO	National	Association for persons with visual impairments	Generalist and assistive technology
Sweden_04	F	Public	National	Anti-discrimination office	Equality of opportunity, anti-discrimination
Serbia_01	DNP	NGO/DPO	National	President	Community living, social enterprise
Serbia_02	DNP	NGO/DPO	DNP	President	Mental health, disability rights
Serbia_03	DNP	Public	Regional	Head of division in psychiatric hospital	Mental health, activism
Serbia_04	DNP	NGO/DPO	National	DPO representative	Rights of persons with visual impairments
UK_01	M	DNA	National	Disabled academic	Disability /general
UK_02	M	DNP	DNP	Disability activist	Disability /general
UK_03	F	NGO/DPO	National	Policy and research head at a National Mental Health Charity	Mental health
UK_04	DNP	DNP	DNP	Statutory equalities and human rights monitoring	Generalist, UNCRPD and employment
Italy_01	DNP	NGO/DPO	National	President of NGO	Policies on disabilities
Italy_02	DNP	Public	National	Official from Ministry of Labour	Disability and employment policies
Italy_03	DNP	DNP	National	President of psychiatrists association	Psycho-social problems
Italy_04	M	Public	Regional	Special counsellor on disabilities	Policies on disabilities general

DNP = data not provided

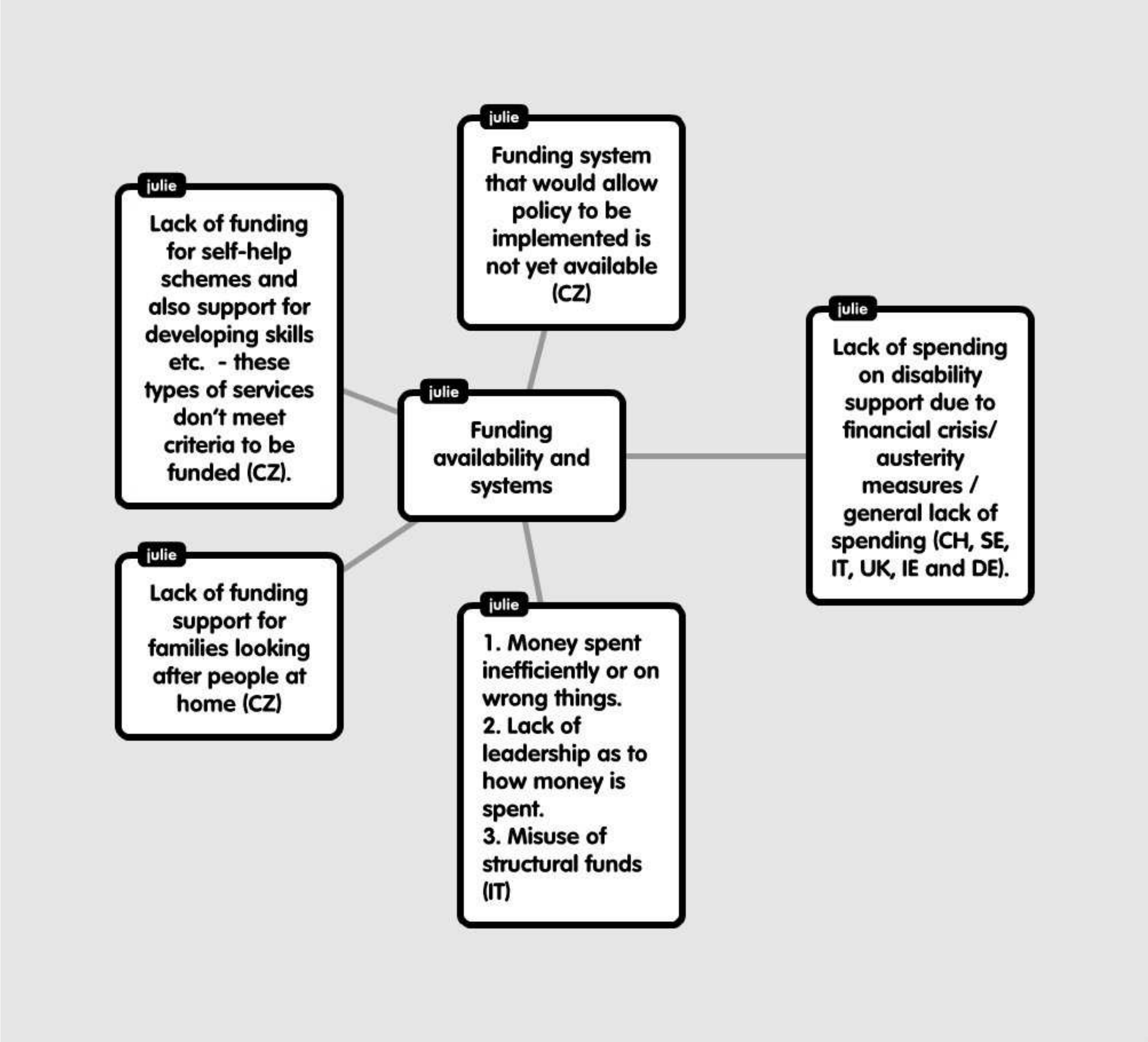
DNA = data not available ‘

Annex 2: Diagrammatic summaries of the themes and sub-themes emerging for barriers to community living

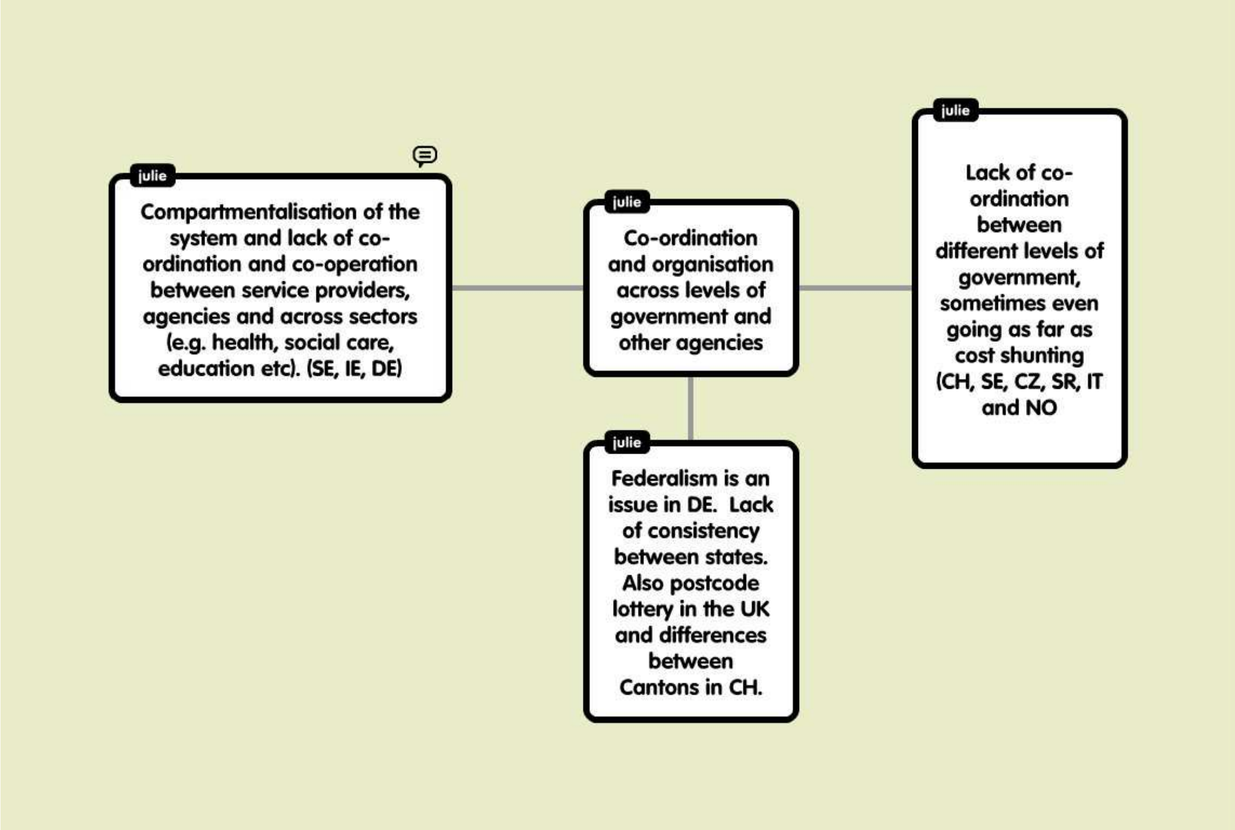
1. Policy and politics



2. Funding availability and systems



3. Co-ordination and organisation across levels of government and other agencies



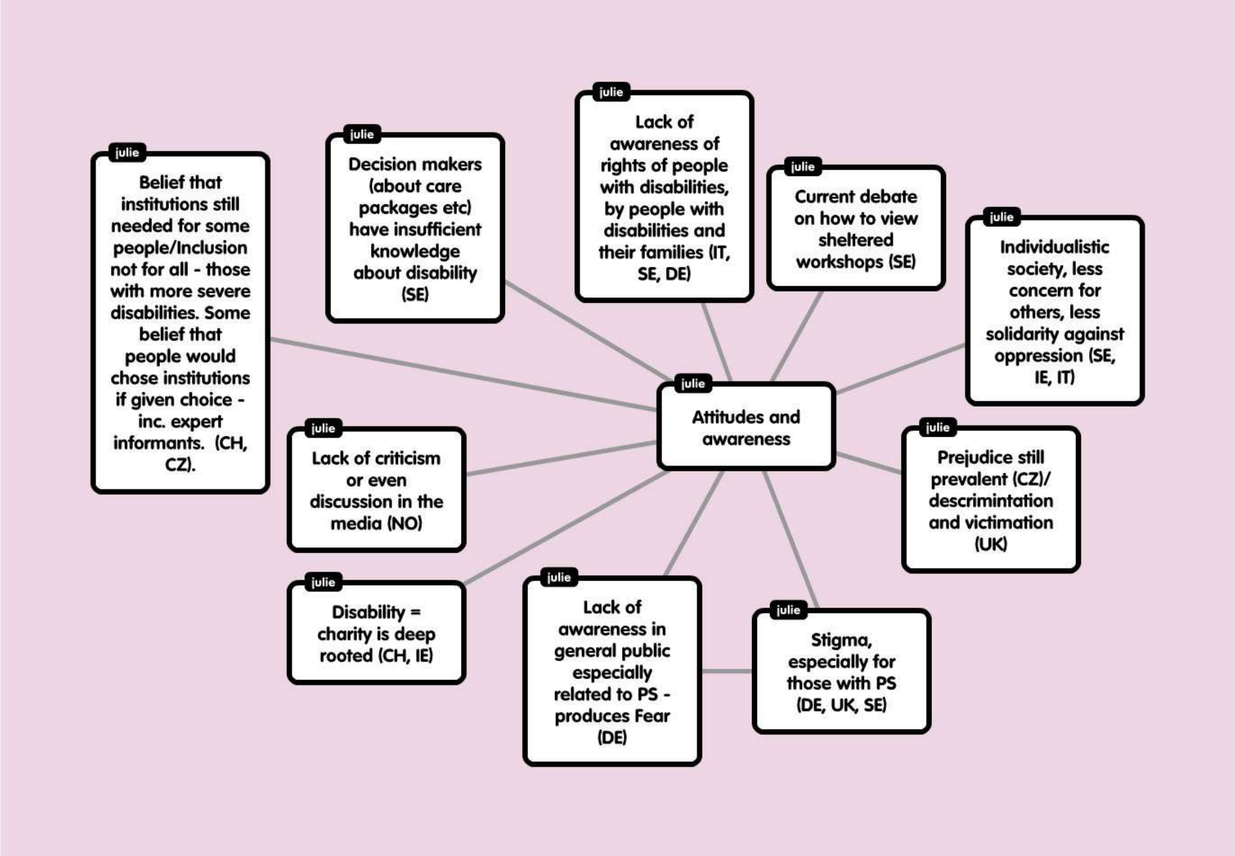
Compartmentalisation of the system and lack of co-ordination and co-operation between service providers, agencies and across sectors (e.g. health, social care, education etc). (SE, IE, DE)

Co-ordination and organisation across levels of government and other agencies

Lack of co-ordination between different levels of government, sometimes even going as far as cost shunting (CH, SE, CZ, SR, IT and NO

Federalism is an issue in DE. Lack of consistency between states. Also postcode lottery in the UK and differences between Cantons in CH.

4. Attitudes and awareness



Attitudes and awareness

Belief that institutions still needed for some people/Inclusion not for all - those with more severe disabilities. Some belief that people would chose institutions if given choice - inc. expert informants. (CH, CZ).

Decision makers (about care packages etc) have insufficient knowledge about disability (SE)

Lack of awareness of rights of people with disabilities, by people with disabilities and their families (IT, SE, DE)

Current debate on how to view sheltered workshops (SE)

Individualistic society, less concern for others, less solidarity against oppression (SE, IE, IT)

Prejudice still prevalent (CZ)/ descrimintation and victimation (UK)

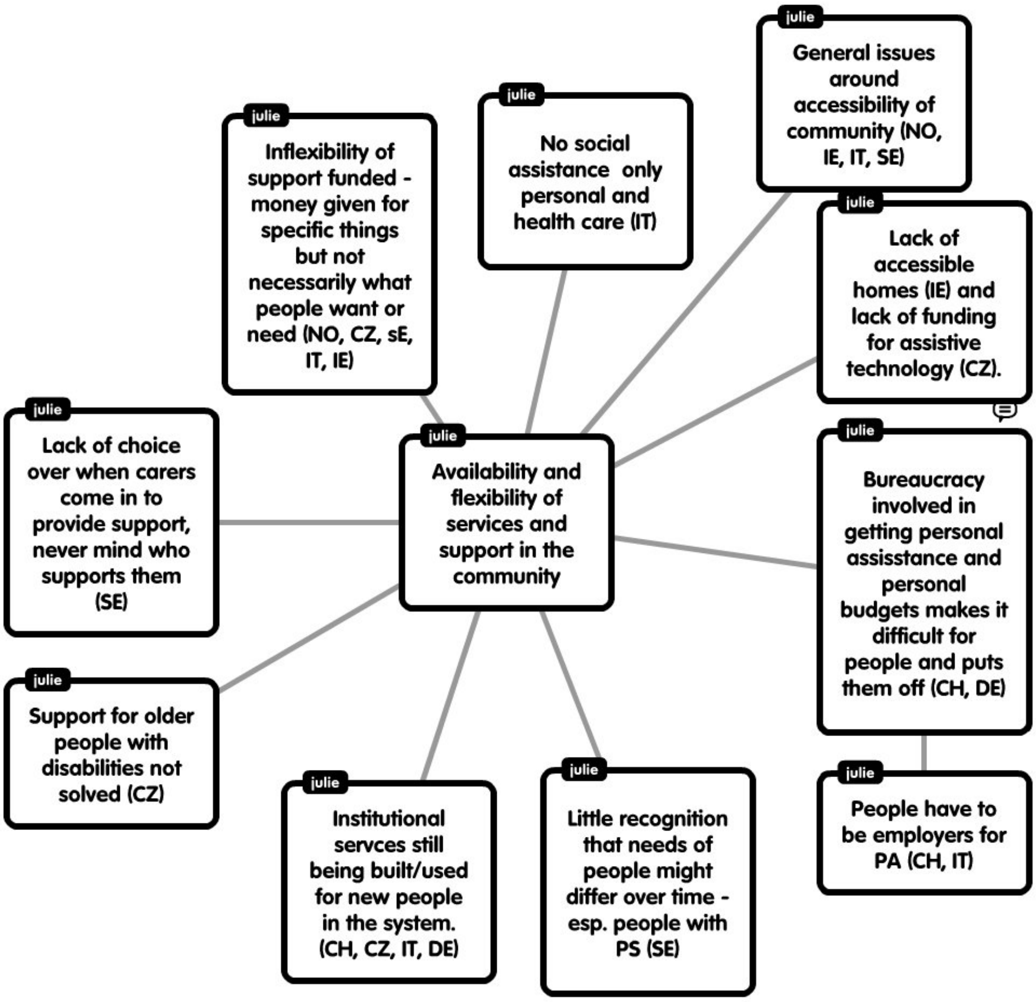
Stigma, especially for those with PS (DE, UK, SE)

Lack of awareness in general public especially related to PS - produces Fear (DE)

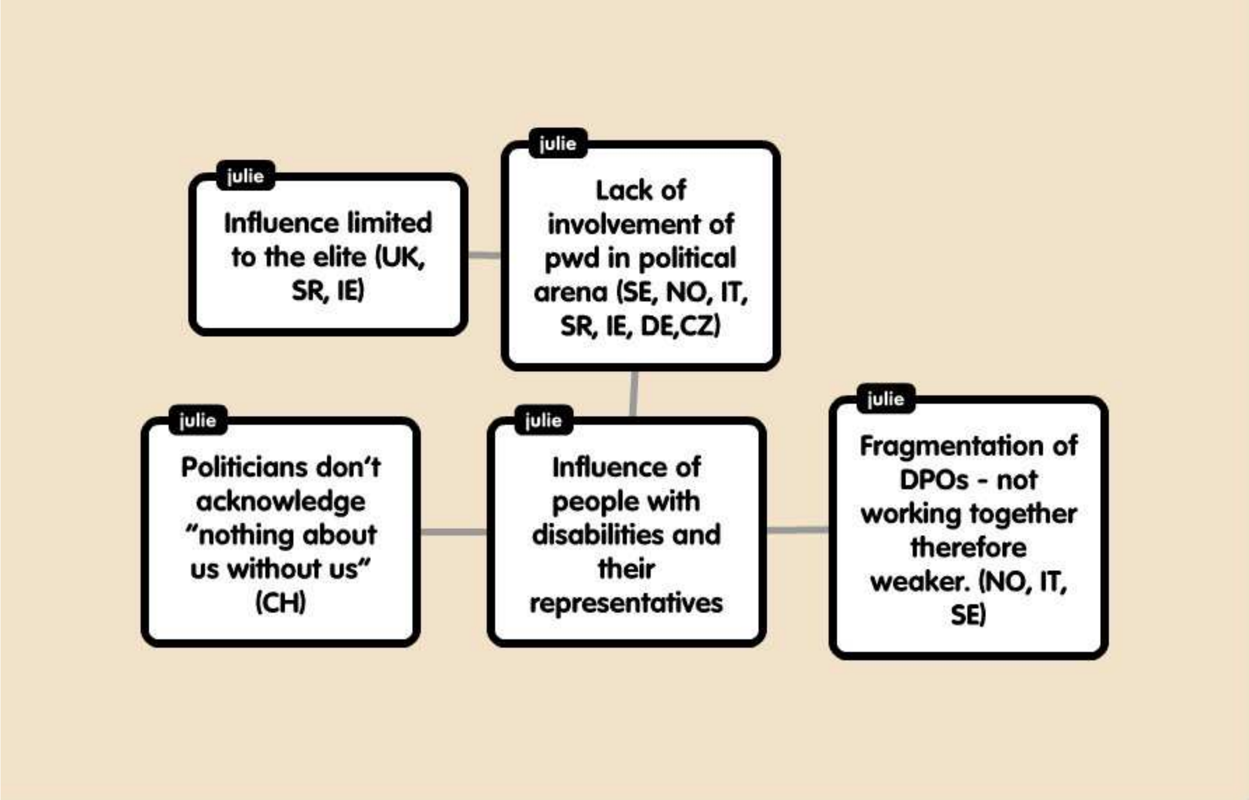
Disability = charity is deep rooted (CH, IE)

Lack of criticism or even discussion in the media (NO)

5. Availability and flexibility of services and support in the community



6. Influence of people with disabilities and their representatives



Influence limited to the elite (UK, SR, IE)

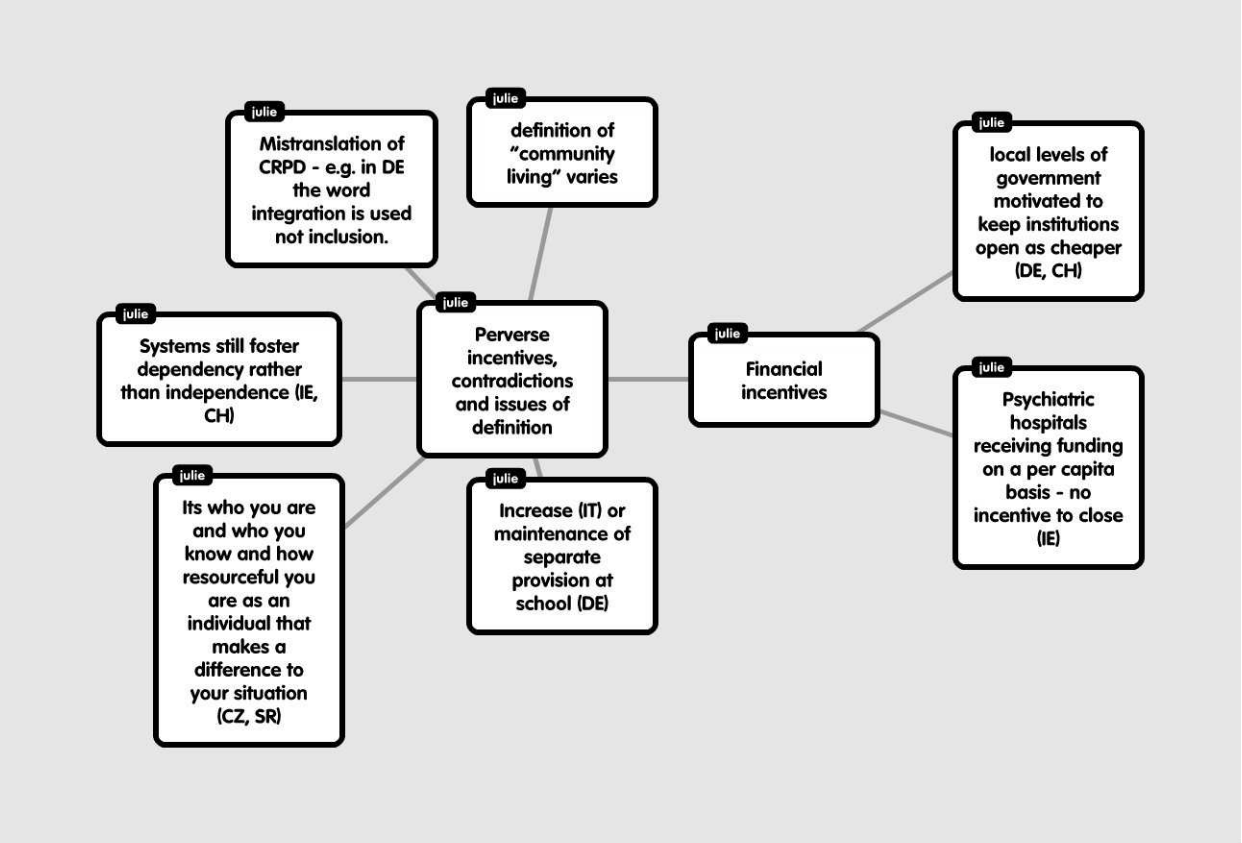
Lack of involvement of pwd in political arena (SE, NO, IT, SR, IE, DE,CZ)

Politicians don't acknowledge "nothing about us without us" (CH)

Influence of people with disabilities and their representatives

Fragmentation of DPOs - not working together therefore weaker. (NO, IT, SE)

7. Perverse incentives for the maintenance of institutional provision, contractions in the system and issues of definition and conceptualisation



Perverse incentives, contradictions and issues of definition

Mistranslation of CRPD - e.g. in DE the word integration is used not inclusion.

definition of "community living" varies

Systems still foster dependency rather than independence (IE, CH)

Its who you are and who you know and how resourceful you are as an individual that makes a difference to your situation (CZ, SR)

Increase (IT) or maintenance of separate provision at school (DE)

Financial incentives

local levels of government motivated to keep institutions open as cheaper (DE, CH)

Psychiatric hospitals receiving funding on a per capita basis - no incentive to close (IE)

Annex 3: Suggested categories for datasets on living situation and support

It is recognised that it would be very difficult to gather information about people living on their own or with family with no support or involvement from social or health care services. As such the list below focuses on those who are receiving support of some description for accommodation and/or for living (i.e. to access healthcare, personal care, social and emotional needs, leisure, employment). Data should include some indication of age, gender, and nature of disability

1. Living in own home (owned or rented, on own or with spouse and/or children, or with a friend of their choice) or in the family home, with paid support for personal and/or health care, domestic help or support to access the community for shopping, leisure, work, medical appointments etc. Ideally, this should be broken down by number of hours, perhaps into categories such as less than 1 hour per day, 2-4 hours per day, 4-10 hours per day, more than 10 hours per day.

2. Living in an apartment (on own or with spouse and/or children, or with a friend of their choice) that is dispersed in the community (i.e. not attached to an intuition or residential service or part of a campus style setting, or a block of flats just for people with disabilities but an ordinary house/flat in the community) but provided by an NGO or local authority (person is not paying rent – accommodation is included in the care package).

3. Living in dispersed rented shared accommodation with other people with disabilities – paying rent to private rental market or to government under social housing scheme and living with less than five other people with disabilities – may not have had much choice about who they live with initially.

4. Living in dispersed shared accommodation as for 3) above but accommodation provided by NGO or State as part of care package – person does not have tenancy rights.

5. Living either in shared houses or individual flats that are clustered so that the group is more than six people but less than 20 people living in the same location (and no one without a disability living (not including staff) in the same location). Staff support might vary from occasional drop in support to 24-hour support according to individuals' needs.

6. Living in a large shared house/smaller institution or on a larger campus – between 20 and 100 people in one location (staff will usually be there 24 hours a day).

7. Living in a larger institution (more than 100 people).