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# Choice and control: the right to independent living

Experiences of persons with intellectual disabilities  
and persons with mental health problems  
in nine EU Member States

This report addresses matters related to the principle of non-discrimination (Article 21) and the integration of persons with disabilities (Article 26) falling under Chapter III 'Equality' of the Charter of Fundamental Rights of the European Union.

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Cataloguing data can be found at the end of this publication.

Luxembourg: Publications Office of the European Union, 2013

ISBN 978-92-9192-952-8  
doi:10.2811/88538

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*Printed in Luxembourg*

PRINTED ON PROCESS CHLORINE-FREE RECYCLED PAPER (PCF)





# Choice and control: the right to independent living

Experiences of persons with intellectual disabilities  
and persons with mental health problems  
in nine EU Member States





# Foreword

Recent years have witnessed major developments in the European Union (EU) and internationally in the protection of the fundamental rights of persons with disabilities. The adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006 was a significant milestone in asserting the rights of persons with disabilities. The EU concluded the convention on 23 December 2010, making it the first international human rights treaty to which the EU has acceded. In addition, as of April 2012, all EU Member States had signed the treaty and 20 had ratified it, with more to come in the near future. These ratifications illustrate the Member States' dedication to the rights-based approach to disability, and are a clear sign that the EU and its Member States are committed to improving the lives of persons with disabilities.

The CRPD marks a paradigm shift from an understanding of disability as a medical condition to one that sees disability as the effect of an interaction between an individual's impairment and the barriers society creates. Article 19 of the CRPD, which guarantees the right to live independently, throws the spotlight on this shift in perspective. It outlines the need to offer persons with disabilities choice and control over their living arrangements, access to services provided to the general public and, if needed, individualised support.

At the core of the CRPD are the concepts of self-determination, participation and inclusion. These principles underpin the work of the European Union Agency for Fundamental Rights (FRA) on the fundamental rights of persons with mental health problems and persons with intellectual disabilities. This report, which is based on in-depth interviews with persons with disabilities in nine EU Member States, presents a portion of this work. Those interviewed have spoken about their experiences and conditions of everyday life; their voices help us to understand what the right to live independently means in practice.

The right to live independently, this report shows, is a multifaceted concept encompassing more than policies on deinstitutionalisation alone. While these are of tremendous importance, for community living to be truly successful, deinstitutionalisation should be accompanied by a range of social policy reforms in areas of education, healthcare, employment, culture and, not least, support services. Only then will the rights enshrined in the CRPD become a reality for all persons with disabilities.

The report points to the need for a discussion of what making choice and control a reality for persons with disabilities will mean for EU Member States and provides some evidence on which to base such a discussion. The research brings to light the situation of two groups of individuals who have long suffered discrimination and social exclusion and whose fundamental rights situation demands urgent action. The findings are also relevant to the situation of all persons with disabilities. The report shows that protecting and fulfilling the rights of persons with disabilities is not just about putting in place the appropriate legal instruments and safeguards but also about ensuring that society itself is prepared to support the full and equal integration of persons with disabilities. This can only be achieved if persons with disabilities are given the opportunity to exercise choice and control over their daily lives.

**Morten Kjaerum**

*Director*



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# Executive summary

## Background

The chance to grow up with one's family, to live where and with whom (as adults) one chooses, to participate in the life of one's local community and to make one's own life choices are opportunities which most of humanity takes for granted. The importance of this chance is recognised by the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), of which Article 19 sets out a right to live independently and be included in the community recognising that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

The CRPD adopted by the UN General Assembly in December 2006 is the most wide-reaching and comprehensive international instrument in the area of disability rights. It was drafted with an unprecedented degree of civil society involvement, in particular from organisations representing persons with disabilities. The convention provides a unique frame of reference through which to evaluate the present situation of persons with disabilities, as well as tools to measure progress in enabling them to live independently and participate in community life on an equal basis with others.

For a person with disabilities the right to independent living entails more than deinstitutionalisation and support options. While these are essential for an individual's self-determination, other issues are equally important. For persons to have choice and control over their lives they should be, for example: allowed to vote in elections and stand for public office; facilitated to work through reasonable adjustments in the workplace; and allowed to enter legally binding contracts. Finally, they should not be unduly deprived of their liberty by administrative means. These activities empower an individual to exercise the choice and control which is essential for living independently.

This report outlines the findings of interview-based research carried out in 2010 and 2011 in nine EU Member States with persons with mental health problems and persons with intellectual disabilities. The research examined how they experience the principles of autonomy, inclusion and participation in their day-to-day lives. The report also provides some examples of promising practices.

The qualitative research generated a wealth of information about experiences in different parts of the EU, giving a platform to those individuals whose voices are

seldom heard. The nature of this type of research does not allow for a sample large enough to be statistically representative of the total population of persons with mental health problems or persons with intellectual disabilities. Although the experiences outlined here cannot be taken to represent the situation across the EU as a whole, they can illuminate and explain how the lives of individuals are affected by laws and policies, or by the lack of them.

## Methodology

The fieldwork research was carried out between November 2010 and July 2011 in Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom. One-to-one and focus group interviews with a limited number of persons with mental health problems and persons with intellectual disabilities allowed for an in-depth understanding of the issues. Photographs taken by respondents and with their informed consent are included in Annex 2. The research also held focus group interviews with stakeholders with expertise and experience relating to persons with mental health problems and with persons with intellectual disabilities in each of the nine countries. Stakeholders represented organisations or bodies working in the field, for example user-led organisations or groups, government departments, ombudsman offices or national human rights institutions and professional bodies, such as psychiatrists and social workers. At a peer review meeting, organisations and groups representing persons with mental health problems and persons with intellectual disabilities from the countries covered by the fieldwork discussed the initial findings of the research. The results do not claim to be representative of all persons with intellectual disabilities or mental health problems, but they do provide a rich insight into the issues and problems those with such disabilities face in everyday life across several EU countries.

## The situation of persons with intellectual disabilities

The research shows that opportunities and support for people with intellectual disabilities to live independently vary. According to the respondents, barriers and systems – whether in the form of long-term care institutions, institutional regimes, lack of daily living support, inaccessible workplaces and services, stigmatisation and discrimination or restrictions on legal capacity – act to exclude them from the mainstream of community life. The interviews highlight the obstacles

which impede people with intellectual disabilities from living independently and participating in community life, but they also offer examples of good practice. Indeed, respondents' characterisation of the transition to independent living as an on-going process which, however, remains far from realisation is a consistent theme of this research. Respondents describe their lives as restricted by a general lack of power and opportunity, but they say that as power and opportunity are gradually transferred to them they undergo a form of liberation. Many are caught between these two states.

Respondents spoke of a lack of choice and control over where and with whom to live and attributed this mainly to two factors. First, limited alternative housing and support options restrict the number of available and suitable living arrangements in the community. In a number of countries respondents said that this reduces their choices to either living with their parents and relatives or moving into large social care institutions. Second, many people with intellectual disabilities do not have the financial resources needed to live independently. Respondents in this research expressed a desire for a 'place of their own' but frequently had insufficient income to rent or buy their own accommodation.

The research also shows that outside the home autonomy and inclusion are similarly circumscribed. According to research respondents, employment in the open labour market is out of reach for many because: segregated education makes the transition from education to employment particularly difficult; employers fail to make reasonable adjustments; and of discrimination on the grounds of disability. These barriers leave people with intellectual disabilities with little prospect of getting a job, although work is a way to overcome boredom and isolation, secure inclusion in community life and gain independence. In the absence of employment, alternative daily activities, such as day centres, become even more important, for they offer a way to spend time away from residential accommodation, provide structure, build relationships and access support services. Respondents argued that such activities are, however, frequently segregated from mainstream community life and often do not satisfy individual needs or interests. Furthermore, the 'risk-avoidance' practices of care takers and family members often hinder choice and control over cultural and leisure activities.

In terms of personal life, forming intimate relationships and establishing a family are often subject to significant restrictions. Parents frequently play a particular role in sanctioning relationships; an issue that respondents indicated can be a source of conflict between individuals and their families. Respondents argued that administrative burdens, such as those arising, for instance from disputes on ordinary residence, can also limit the ability

to maintain intimate relationships by preventing people from moving from one local authority area to another in order to live together.

For many people with intellectual disabilities independent living requires support in their daily lives. According to research respondents, personal assistants, freely chosen by the person with intellectual disabilities themselves, can promote autonomy and inclusion by helping to develop daily living skills, facilitating participation in community and cultural life, dealing with financial matters and opening up access to goods and services. Similarly, personal budgets and direct payments can empower people by giving them control over who to employ and what services and support they provide. If their assistants simply perform such tasks and decide on their behalf, people with intellectual disabilities will not be able to build up the knowledge and daily skills for an independent adult life and their dependence will increase.

Another crucial aspect of independent living is the ability to participate in public and political life, in terms of exercising the right to vote or through involvement in self-advocacy organisations. Many people with intellectual disabilities are legally deprived of the right to vote, while others lack awareness of political events and find the political process inaccessible. The self-advocacy movement helps to counteract this political isolation by conveying the concerns of people with intellectual disabilities to public authorities, and by advocating for their views to be heard in policy and decision making. Self-advocacy and peer support organisations can also provide wider services that help to empower people with intellectual disabilities, including training, rights awareness and support to access justice in cases of poor or unfair treatment.

While the absence of choice and control in living arrangements, daily activities and support services are pervasive obstacles to independent living, research respondents also mentioned specific barriers impeding autonomy and inclusion, such as restrictions on legal capacity. Such restrictions can deprive people with intellectual disabilities of the ability to make decisions – both major and minor – about how they live their lives. Administrative barriers also curtail individuals' scope to make choices about their lives through complex and changing rules and regulations that can alter eligibility for benefits and support services. Inaccessible information reduces their awareness of entitlements and administrative processes. Similarly, respondents mentioned the need for legal systems to be adapted to the needs of people with intellectual disabilities to address difficulties in recourse to justice in cases of maltreatment, which can include lack of legal support and the fear of not being believed.



Less tangible or visible barriers also serve to undermine choice and control. According to respondents, despite progress towards deinstitutionalisation, institutional cultures often suffer from a lack of privacy, rigid daily routines and power inequalities between staff and patients. In the community, bullying, harassment and verbal and physical abuse are widespread, respondents say. Some professionals and parents, they add, have paternalistic attitudes and practices that increase dependency and impede participation. These negative attitudes and low expectations are based on the presumption that people with intellectual disabilities lack the intrinsic capacity to exercise rights responsibly, to make choices for themselves and to live independently in the community.

Respondents highlighted how financial restrictions affect the daily lives of people with intellectual disabilities in complex and profound ways. The lack of employment opportunities means many people are reliant on benefits and other state support, which limits their ability to participate in a range of activities accessing goods and services that are required for meaningful independent living. Participants also noted that, given the current economic climate, eligibility criteria for community-based support are being tightened, which can have a detrimental impact on opportunities to live independently and be included in the community. Some respondents in this research expressed concern that as a result they may have no choice but to return to living in an institution. Austerity measures also affect self-advocacy groups and other civil society-led support measures, with many shutting down or scaling back their activities. Together, these developments could undo some of the positive results achieved in relation to integration and participation of people with intellectual disabilities on an equal basis with others.

## The situation of persons with mental health problems

Again, the research shows that the extent to which people with mental health problems are able to live independently in the community varies considerably, reflecting the degree and various types of support available in different countries. For many respondents, barriers and processes – ranging from long, and sometimes involuntary, stays in psychiatric hospitals, restrictions of legal capacity and financial pressures to a lack of reasonable accommodations at work, insufficient support services, and stigmatisation and discrimination – work to exclude them from community life. Respondents also speak, however, of promising practices that help people with mental health problems to exercise more choice and control over their lives. They describe being empowered by appropriate support

and accommodative systems, while reflecting on the restrictions that continue to undermine their autonomy. Although considerable progress has been made in this area, much more remains to be done.

Choice and control over living arrangements is a key issue for people with mental health problems. In some countries, respondents said that many people live alone or with people they have chosen, giving them both control over their daily lives and a place of refuge. Two interrelated factors determine whether it is possible to live in this way. First, the availability of appropriate housing in the community and of support for independent living; lack of these elements leaves little choice but to live with families or in group-based accommodation with varying degrees of institutional culture. Second, the level of income and/or of state benefits restricts the choices available to rent or buy a home. Respondents also described the lack of choice over residence area given a reliance on subsidised housing. While none of the respondents interviewed lived in institutions at the time of the interviews, many expected that they would again spend time in psychiatric hospital in the future, and were concerned about the impact it would have on their ability to live independently in the long term.

According to respondents, people with mental health problems often have difficulties in finding employment both because of low levels of educational attainment – the onset of mental health problems often occurs during late adolescence and affects post-secondary education – and because of prevailing prejudice and an unwillingness to reasonably accommodate their needs. In the absence of opportunities on the open labour market, many seek – or are given – jobs in sheltered workshops or with voluntary organisations. In the absence of proper paid work these activities offer social interaction, the feeling of contributing to society and a sense of purpose. Such sheltered workshops, however, isolate people with mental health problems from community life thus reinforcing their stigmatisation and undermining their prospects of getting and maintaining paid work on the open labour market.

Respondents also spoke of difficulties they encounter when interacting with healthcare services and about insufficient or inappropriate community-based mental health support. They argued that general practitioners frequently fail to take physical complaints seriously, assuming that they are related to their mental health. Similarly, treatment for physical illness can be restricted on the basis of mental health problems, while information about diagnosis, medication and potential side effects is often lacking. Where available, talking and other non-medicinal therapies, as well as local centres offering flexible support and a variety of activities, are highly prized. Respondents stressed, however,

the need to improve availability of and access to such services, and particularly the importance of ensuring that they reflect the ever-changing nature of mental health problems.

People with mental health problems need access to a range of different forms of support, respondents said, in order to be able to live independently and have genuine choice and control over their lives. In terms of formal support, for instance, assistance with the development of independent living skills can facilitate the transition from institutional or family living arrangements to community-based ones. In the community, state-funded advocates or agents who provide particular services such as support with finances are highly valued, while others can benefit from technical devices that can, for example, automatically check that household appliances are switched off before a person leaves the house, and from self-developed techniques to avoid difficult tasks during periods of mental ill-health. Informal support mechanisms also serve to facilitate autonomy and inclusion. Many respondents identified the discussion of issues and informal advice from family and friends, for instance, as key sources of support. They also stressed the importance of representative and user-led organisations, which, alongside their peer-support role, offer services and practical assistance with navigating different support options. Concern about the limited – and sometimes declining – availability of many support options emerges strongly as a theme of this research.

In some countries, respondents noted the valuable role representative organisations play both through peer support and by giving a voice to people with mental health problems in the shaping of service delivery and policy. In other countries, however, respondents say such organisations face considerable challenges in terms of capacity or political support, leaving people with mental health problems isolated, unsupported and less able to influence the shape of policies affecting them. Strong networks of user-led organisations can help to inform and empower people with mental health problems, giving them a means through which to articulate, and campaign for, their needs and to raise awareness of their rights.

Legal and societal barriers can also impede the choice and control people with mental health problems can exercise over their own lives. According to the respondents, many people are formally deprived – either totally or in part – of their legal capacity, potentially leaving them unable to sign contracts for employment or to take decisions about their property and finance. These choices are instead made by guardians whom they have often not selected themselves. This lack of decision-making power is particularly acute in relation

to the involuntary placement or treatment of people with mental health problems in psychiatric hospitals. Respondents also spoke of informal restrictions, for instance when families restrict choice and control by interfering excessively in their private lives. Moreover, despite changes intended to make legal systems more accessible and responsive to people with mental health problems, many obstacles continue to affect access to justice. Lack of awareness of complaint or redress mechanisms, insufficient legal support and fear of stigmatisation can affect people's decisions to lodge a formal complaint.

Societal barriers are also important. Institutional regimes limit the choice and control not only of those in psychiatric hospitals and large social care homes, respondents say, but also of those in some smaller group homes where institutional cultures persist. Respondents recalling their time in institutions described them as characterised by regimented daily routines and a lack of privacy, and marked by unequal power relationships between staff and residents. In the community, stigmatisation and discrimination on the basis of mental health are common occurrences. Entrenched misconceptions about people with mental health problems lead to abuse and bullying from the public, and can undermine personal relationships and interaction with service providers and medical professionals. This contributes to social isolation and reduced opportunities to participate in society. Fear of possible recriminations means that many do not disclose their mental health status to others, depriving them of the possibility to benefit from reasonable adjustments.

Finally, economic factors operate to exclude and marginalise people with mental health problems and deny them access to opportunities on an equal basis with others. Research respondents noted that many people, in the absence of paid employment, are reliant on benefits for all or most of their income. Such benefits are often not enough to allow people to make choices about where and with whom to live, to access support and to participate in activities that would enable greater inclusion in the community. Dependence on benefits exacerbates the stress brought on by repeated changes to the benefit system or to entitlement thresholds, as well as anxiousness associated with the need to prove the severity of mental health problems in order to renew one's disability status. In addition, austerity measures taken in the context of the economic crisis often result in cuts in services and social security benefits, which risks holding back progress towards meaningful independent living.





## The way forward

The gradual transition to independent living as an on-going process is for people with disabilities a form of liberation as they gradually gain more control over their own lives and are able to make their own choices about how to live. The positive initiatives and testimonials presented in this report show the positive impact that innovative policies facilitating choice and control are already having on persons with disabilities. While progress is being made a consistent theme of this research is, however, that there remains a long way to go before the rights enshrined in the CRPD become a reality. In this regard key initiatives in policy, law and practice, such as those listed below, can facilitate progress in helping persons with mental health problems and persons with intellectual disabilities to live more independently within the community.

- Legal and administrative measures to support decision making by people with mental health problems or intellectual disabilities.
- Measures to ensure that adequate, good quality and freely-chosen personalised support for independent living is made available independently of the type of living arrangement.
- Measures to ensure that support is available to the families of children with intellectual disabilities or mental health problems and to parents with intellectual disabilities or mental health problems to enable them to look after their children.
- Measures to enhance the financial independence of people with intellectual disabilities or mental health problems through social security and employment promotion programmes.
- Measures combating discrimination and ensuring equal access to employment and key areas of social life, such as education, culture, leisure and the provision of goods and services, including affirmative action to remedy existing inequalities.
- Measures to develop appropriate community-based living arrangements that give a meaningful choice over where to live, making appropriate use of the EU's structural funds.
- Measures to reduce any administrative burdens associated with accessing and using public support services, including through the provision of accessible and relevant information, particularly regarding entitlements.
- Measures supporting the development of self-advocacy organisations and measures to increase the active participation and involvement in politics and in policy, in programme development and decision making by people with intellectual disabilities and people with mental health problems.
- Measures to support the establishment of more community-based mental health centres and services for people with mental health problems.
- Measures to ensure the political participation of persons with mental health problems or intellectual disabilities. The right to vote is a basic prerequisite for effective involvement in the political process.
- Measures to raise awareness about complaint mechanisms and to support people with mental health problems and people with intellectual disabilities to access justice and participate in judicial procedures.



# Background

Persons with intellectual disabilities and persons with mental health problems have for centuries suffered stigmatisation and discrimination. Isolated from mainstream society and kept away from public view, they lived in a variety of institutions, asylum facilities and psychiatric hospitals.<sup>1</sup> Deinstitutionalisation as a policy goal started in Europe in the late 1960s and early 1970s<sup>2</sup> and has been implemented at various speeds and in different ways.<sup>3</sup>

According to research over one million people live in institutions in Europe, including the EU and neighbouring countries.<sup>4</sup> Persons with intellectual disabilities or with mental health problems feature disproportionately amongst them.<sup>5</sup> Although precise statistics are not available, research suggests that persons with intellectual disabilities make up over a quarter of this population and persons with mental health problems are the next largest group.<sup>6</sup>

There is no commonly agreed definition of an 'institution', as the term is used in different ways across different countries. In the context of disability, the term 'institution' is widely used to refer to forms of living arrangements which separate persons with disabilities from their families and local communities, and which do not permit them full choice and control over their day-to-day lives. The World Health Organization (WHO) provides the following definition of an 'institution':

*"Any place in which persons with disabilities, older people, or children live together away from their families. Implicitly, a place in which people do not exercise full control over their lives and their day-to-day activities. An institution is not defined merely by its size."*<sup>7</sup>

The right of persons with disabilities to live independently and take decisions is not only affected by their stay in such institutions. It is also reflected in aspects of law and policy. One example, which has been a focus of the disability rights movement, is guardianship legislation. Legal definitions of 'guardianship' differ between countries but share a common denominator, namely that a guardian has legal authority to care for the personal and proprietary interests of another. Guardianship regimes are applied to minors and persons who are incapacitated, or to persons with a disability.

Under guardianship laws, individuals may be deprived of all or some of their legal capacity, for example their right to marry, vote, write a will, sign an employment contract or buy assets, such as a house.<sup>8</sup> Another example is legislation on involuntary detention and psychiatric treatment of persons with mental health problems.

Independent living today is a holistic concept addressing several elements that enable persons with disabilities to be included in society on an equal basis with others. In this way, independent living has become "about disabled people having the same level of choice, control and freedom in their daily lives as any other person".<sup>9</sup>

## The United Nations Convention on the Rights of Persons with Disabilities

In December 2006, the UN General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD), profoundly altering how international law views the rights of persons with disabilities. This convention, drafted with an unprecedented degree of involvement from civil society and, in particular, from organisations representing persons with disabilities,<sup>10</sup> details the essential building blocks for ensuring the respect, protection, promotion and fulfilment of the human rights of persons with disabilities. The CRPD does not create new rights, but rather takes existing rights and puts them into the disability context, detailing the steps that must be taken to make them practicable for persons with disabilities. It brings together civil and political rights with economic and social rights, creating a comprehensive framework built on different facets of human rights protection.

The CRPD, because of its clarity and detail about what human rights mean in the disability context, provides not only a unique frame of reference through which to evaluate the present situation of persons with disabilities, but also the tools to measure progress made in enabling them to live independently and participate in community life on an equal basis.

Article 19 of the CRPD entitled 'living independently and being included in the community' is of particular relevance to this research. It is the first provision in a UN human rights treaty to expressly articulate a right to be

1 Goffman, E. (1961).

2 For more information, see Ericsson, K. and Mansell, J. (1996), and Mansell (2006).

3 For more information on deinstitutionalisation, see Fakhoury, W. and Priebe S. (2000), pp. 187–92.

4 Mansell et al. (2007).

5 Pfeiffer, J. et al. (2009) and Townsley, R. et al. (2010), section 3.3.

6 Pfeiffer, J. et al. (2009).

7 WHO and World Bank (2011), p 305.

8 See: <http://mdac.info/guardianship>. See also Keys, M. (2009); and Bartlett, P. et al. (2007), Chapter 6.

9 UK Office for Disability Issues, Independent Living Strategy, available at: <http://odi.dwp.gov.uk/odi-projects/independent-living-strategy.php>.

10 Tromel, S. (2009).

furnished support in order to live independently and participate in community life.

### **Article 19 of the Convention on the Rights of Persons with Disabilities**

#### **Living independently and being included in the community**

“States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to 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;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

The convention does not define the scope of the term ‘independently’. It can be argued, nevertheless, that the term is not used in the narrow sense of performing tasks alone and unassisted. Instead, the CRPD links the notion of independence to choice and control over daily living arrangements rather than to unaided functional ability. When assistance is required it should be provided in a way that empowers a person to “to support living and inclusion in the community, and to prevent isolation or segregation from the community.” (Article 19 (b))

While Article 19 codifies the right to independent living, to be made meaningful in its fullest sense it must be read in conjunction with a number the convention’s other articles, because the concept of independent living brings together many aspects of an individual’s life, and thus requires the realisation of many other human rights. Article 5 of the CRPD, for instance, lays down the duty on States Parties to prohibit discrimination based on disability. Discrimination, as Article 2 of the CRPD makes clear, includes a failure to provide reasonable accommodation. ‘Reasonable accommodation’ is itself defined as a ‘necessary and appropriate’ modification

or adjustment which is needed in a ‘particular case’ to ensure access for a person with disabilities to a particular right or freedom ‘on an equal basis with others’ and which does not impose a ‘disproportionate or undue burden’. Discrimination thus includes both the notion of less favourable treatment on grounds of disability and the failure to provide reasonable accommodation.

The need for the provision of support in order to facilitate independent living and community participation also lies at the heart of Article 26. This requires States Parties to take “effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”. These measures must include the provision of voluntary habilitation and rehabilitation services based on assessments of an individual’s needs and strengths and available as close as possible to the person’s own community, also in rural areas, supporting participation and inclusion in the community. In Article 26 (3), a specific obligation is set out to promote “the availability, knowledge and use of assistive devices and technologies” relating to habilitation and rehabilitation.

Article 12 supports inclusion and participation by recognising that persons with disabilities are ‘persons before the law’ and have legal capacity on an equal basis with others. Indeed paragraph 3 of this article assigns an explicit duty to States to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”. In this way the convention facilitates a shift away from ‘substituted decision-making’ towards more individually-tailored systems of support, based on respect for the autonomy and dignity of the individual.

Article 28 of the CRPD on standard of living and social protection is also of relevance to independent living, in particular its references to the need to ensure access to poverty reduction schemes and assistance with “disability-related expenses, including adequate training, counselling, [and] financial assistance [...]”. Poverty is often closely linked to barriers faced in obtaining and retaining employment. In this regard it should be noted that Article 27 of the CRPD requires employers to prohibit discrimination on the grounds of disability. Article 27 also places a duty on States to improve employment opportunities for persons with disabilities, for instance by: employing them in public sector jobs; promoting their employment in the private sector through affirmative action policies and other incentives; employment retention and return-to-work policies; and self-employment, entrepreneurship and co-operatives.



Article 29 concerns participation in political and public life. It imposes obligations on States to ensure that persons with disabilities are able to participate, for example by voting and standing for and holding public office on an equal basis with others. It also imposes obligations on them to encourage the formation of representative organisations of persons with disabilities. Article 4 (3) requires States Parties to involve persons with disabilities and their representative organisations in relevant policy making processes.

Article 25 should also be noted: Paragraph (b) requires that the provision of healthcare services which are needed by persons with disabilities “specifically because of their disabilities” include services designed to “minimise or prevent further disabilities”. Paragraph (c) specifies that such services should be made available “as close as possible to people’s own communities, including in rural areas”. In the context of mental health, the obligations imposed by Article 19 on independent living should also be seen in relation to Article 14 (1) (b), which demands scrutiny of the choices and opportunities available to persons with mental health problems as regards their living conditions, stating that the “existence of disability shall in no case justify a deprivation of liberty”.<sup>11</sup> This could have important consequences for involuntary placement and treatment.

Finally, Article 8 of the CRPD imposes awareness-raising obligations on States Parties requiring them to foster respect for the rights and dignity of persons with disabilities; to combat stereotypes and harmful practices; and to promote awareness of their capabilities and contributions. Specific reference is made to the need to raise such awareness through the education system and by encouraging the media to consider these issues when portraying persons with disabilities.

## The European Union and the Council of Europe

The EU became party to the CRPD on 23 December 2010, making the CRPD the first international human rights treaty to be ratified by the EU. Inevitably, the EU’s accession raises novel and challenging legal and political questions about the extent and nature of EU competence in relation to the rights guaranteed by the convention.<sup>12</sup> The EU itself has direct power to legislate in only a limited number of areas, such as discrimination, with the bulk of responsibility for implementing the CRPD lying with EU Member States. Nonetheless, the EU can play a crucial role in raising awareness and promoting Member State implementation of the convention,

particularly by facilitating the sharing of experience, gathering data and identifying good practices.

Furthermore, requirements to respect and realise the fundamental rights of persons with disabilities exist at the heart of EU law: Article 10 of the Treaty on the Functioning of the EU (TFEU) requires the EU to combat discrimination based on disability when defining and implementing its policies and activities; and Article 19 grants it the power to adopt legislation to combat discrimination on grounds of disability. The Equality Employment Directive<sup>13</sup> prohibits direct and indirect discrimination, as well as harassment and any instruction to discriminate on grounds of disability, religion and belief, age, and sexual orientation. It covers the fields of employment and occupation, vocational training and membership of employer and employee organisations. It sets out minimum requirements and Member States may provide for a higher level of protection in national legislation. According to Article 5 of the directive employers are required to take appropriate measures to enable persons with disabilities to access, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on employers (‘reasonable accommodation’).<sup>14</sup>

The Charter of Fundamental Rights of the European Union also contains specific provisions for the realisation of the rights of persons with disabilities associated with independent living and community participation. The entry into force of the Charter as a legally binding instrument means that its requirements now apply to all EU institutions and also to EU Member States in their interpretation and application of EU law.<sup>15</sup> Articles 21 and 26 are the two provisions of the Charter of direct relevance to persons with disabilities: Article 21 prohibits any discrimination on the ground of disability and Article 26 recognises the right of persons with disabilities: “[...] to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.”

The key EU policy instrument in the area of disability is the *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, which was published by the European Commission in November 2010.<sup>16</sup> Its overall aim is “to empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society and in the European economy”. The strategy follows the spirit of the CRPD.

<sup>13</sup> Council Directive 2000/78/EC, OJ 2000 L 303.

<sup>14</sup> For more information, see FRA (2011).

<sup>15</sup> Charter for Fundamental Rights of the European Union, Art. 52.

<sup>16</sup> European Commission (2010a).

<sup>11</sup> See, for instance, Minkowitz, T. (2010), pp. 151-177.

<sup>12</sup> European Council (2010), pp. 0011-0015.

The Council of Europe set out its overarching framework of disability policy in the 2006–2015 Disability Action Plan, adopted by the Committee of Ministers in 2006.<sup>17</sup> Although adopted some months prior to the finalisation of the CRPD, the text reflects the importance of independent living:

*“This action line focuses on enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live. This requires strategic policies which support the move from institutional care to community-based settings ranging from independent living arrangements to small group homes. Such policies should be flexible, covering programmes which enable persons with disabilities to live with their families and recognising the specific needs of individuals with disabilities requiring a high level of support.”<sup>18</sup>*

For its part, the European Court of Human Rights (ECtHR) has issued a series of landmark rulings which refer to various aspects of independent living. Most notably, in the ruling *Stanev v. Bulgaria*,<sup>19</sup> the ECtHR recognised that life in an institution can amount to a violation of the right to liberty. In doing so, the ECtHR took into account the institution’s distance and isolation from the community, its regimented daily schedule, rules on leave of absence, lack of choice in everyday matters and the lack of opportunity to develop meaningful relationships.<sup>20</sup>

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17 Council of Europe, Committee of Ministers (2006).

18 *Ibid.*, Section 3.8.

19 European Court of Human Rights (ECtHR), *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012.

20 For a detailed discussion of the relevant international instruments and an overview of the ECtHR case law, see the Council of Europe, Commissioner for Human Rights (2012b).



# About the report

This FRA report, informed by the CRPD and a human rights-based approach to disability, focuses on issues of choice and control that persons with intellectual disabilities and persons with mental health problems face in their daily lives. The right to live independently epitomises the social model of disability adopted by the CRPD highlighting the social, physical and attitudinal barriers that need to be removed to ensure the full participation of persons with disabilities in society.

The ability to live independently is not only a matter of available accommodation and support options. While these are essential for individuals' self-determination, the full participation of persons with disabilities entails choice and control over other issues, such as political participation through voting and standing for elections, the ability to enter legally binding contracts and not be unduly deprived of their liberty by administrative means. These are all very important dimensions that give an individual the choice and control required for meaningful independent living. These complex and multifaceted issues are addressed in other reports developed by the FRA in its work on disability. The reports examine the right to vote, protection from discrimination and provision of reasonable accommodation, involuntary placement and treatment and legal capacity.<sup>21</sup>

This report presents the findings of transnational qualitative research which generated a wealth of in-depth information about important aspects of the lives of individuals whose voices are seldom heard. In order to collect such information the research relied on relatively small samples of respondents which are not representative of the total target population, namely persons with mental health problems and persons with intellectual disabilities, and focused on selected EU Member States. The findings outlined here cannot, therefore, be taken to represent the situation of all persons belonging to this target population in the EU.

Nevertheless, by providing a deeper understanding of the challenges facing these two groups of people, this research can usefully inform the EU in its efforts to improve the respect, protection and fulfilment of their rights as guaranteed by the CRPD, the Charter of Fundamental Rights of the European Union, as well as informing the development of EU and national legislation in accordance with the EU's European Disability Strategy 2010-2020.

## Methodology

Fieldwork research was carried out in nine EU Member States (Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom) between November 2010 and July 2011 through personal and focus group interviews. The fieldwork was conducted in two parallel and distinct strands in order to respect the important differences between persons with mental health problems and persons with intellectual disabilities. This distinction is also reflected in the analysis of the data. The sample was made up of persons with relatively strong functional abilities who were selected to participate because they could articulate their experiences relatively easily in an interview situation but did not include: persons living in institutions; under guardianship whose guardian refused consent to the interview; and, persons under the age of 18, although adult respondents were asked about their childhood experiences.

The fieldwork was carried out using individual semi-structured interviews and focus groups: individual interviews were held with 115 persons with mental health problems and 105 persons with intellectual disabilities. In each EU Member State at least two focus groups – one with respondents with mental health problems and the other with respondents with intellectual disabilities – discussed the emerging findings of the personal interviews. Additional focus group interviews were conducted in each EU Member State with selected stakeholders with relevant expertise and experience relating to persons with mental health problems or with intellectual disabilities. Stakeholders were representatives of relevant organisations or bodies with an interest in the topics studied. The organisations represented varied between Member States, but, wherever possible, included: a representative of a user-led organisation or group, representatives of government departments, representatives of ombudsman offices or national human rights institutions, and representatives of relevant professional bodies, such as psychiatrists and social workers. At a two-day peer review meeting in Vienna, organisations and groups representing persons with mental health problems and persons with intellectual disabilities from the EU Member States covered by the research discussed the initial results of the fieldwork research.

The FRA administered the project and applied its own rigorous quality control measures including its Scientific Committee. Large part of the background research and the fieldwork was outsourced to the Human European Consultancy, which formed a core research team

<sup>21</sup> European Union Agency for Fundamental Rights (FRA) (2010); FRA (2011); FRA (forthcoming)



composed of Neil Crowther, Edurne Garcia Iriarte, the National Institute for Intellectual Disability (Dublin), Anna Lawson (Leeds University), Oliver Lewis and Jasna Russo (Mental Disability Advocacy Centre), Rachel Stevens (NUI Galway) and Rannveig Traustadottir (University of Iceland). In addition, background studies and fieldwork research at the national level were conducted by national researchers; see Annex 3 for a full list. The research was supported by an ad hoc advisory board composed of the following civil society organisations: European Network of Independent Living (ENIL), the European Disability Forum (EDF), the European Network of (ex) Users and Survivors of Psychiatry (ENUSP), the European Platform of Self Advocates, and Inclusion Europe. In addition, the following experts kindly contributed to the work: Michael Bach (Canadian Association for Community Living), Mark Priestly (Leeds University), Gerard Quinn (NUI Galway), and Lisa Waddington (Maastricht University). The responsibility for the analysis and conclusions lies with the EU Agency for Fundamental Rights.

## Terminology and structure of the report

The preamble to the CRPD acknowledges that disability is an ‘evolving’ concept: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”<sup>22</sup> There are no commonly agreed terms to describe the two groups of persons covered by this report. The terminology varies between jurisdictions, professions and persons with disabilities themselves as well as across geographical regions. During the period when this research was carried out, the terms used by international bodies changed. The Council of Europe Commissioner for Human Rights in his 2009<sup>23</sup> *Viewpoint* and 2010<sup>24</sup> *Human Rights Comment*, for instance, used the collective term ‘persons with mental disabilities’ to refer to ‘persons with mental health or intellectual disabilities’. In his later (2012) *Human Rights Comment*, he referred to “persons with intellectual and psycho-social disabilities”.<sup>25</sup> On the other hand, the European

Commission’s *Pact for Mental Health and Well-Being* refers to ‘people with mental health problems’;<sup>26</sup> while the European Commission’s *Disability Strategy 2010-2020* applies the CRPD term ‘psycho-social disabilities’ in place of ‘mental health problems’.<sup>27</sup> Finally, the WHO’s *World report on disability*<sup>28</sup> speaks of ‘people with mental health conditions’.

In the absence of a common terminology, and after consultation with disabled persons’ organisations (DPOs), this FRA report refers to ‘persons with mental health problems’ and ‘persons with intellectual disabilities’. The term ‘persons with intellectual disabilities’ is used by Inclusion Europe, an association of persons with intellectual disabilities and their families,<sup>29</sup> and the European Platform of Self-Advocates,<sup>30</sup> a network of persons with intellectual disabilities. In the United Kingdom, however, the preferred term is ‘persons with learning disabilities’.<sup>31</sup> The term ‘persons with mental health problems’ was regarded as more accessible to lay persons and non-fluent English speakers, although the term ‘psycho-social disability’ is favoured by the World Network of Users and Survivors of Psychiatry,<sup>32</sup> the International Disability Alliance,<sup>33</sup> a world-wide disability NGO, and the UN Committee on the Rights of Persons with Disabilities.<sup>34</sup> This term is not used by the European Network of (ex) Users and Survivors of Psychiatry (ENUSP).<sup>35</sup> The reluctance of many people with psychiatric diagnoses to identify themselves as ‘disabled’ has spurred a debate about the relationship between conceptions of mental health and disability and contributed to the decision to use the term ‘persons with mental health problems’ in this report.<sup>36</sup>

Intellectual disability and mental health problems are quite separate and distinct phenomena. They have generated different political movements, are associated with different types of experience and response and often have quite different concerns. In this report, in order to avoid repetition, reference is made to ‘persons with disabilities’ in the spirit of the CRPD. This is not intended in any way to undervalue the important differences between persons with intellectual disabilities and persons with mental health problems. The report also refers to ‘groups of persons’, although it is recognised that individual experiences vary greatly.

22 Art. 1 (2) of the CRPD.

23 Council of Europe, Commissioner for Human Rights (2009), *Persons with mental disabilities should be assisted but not deprived of their individual human rights*, Viewpoint, available at: [www.coe.int/t/commissioner/Viewpoints/090921\\_en.asp](http://www.coe.int/t/commissioner/Viewpoints/090921_en.asp).

24 Council of Europe, Commissioner for Human Rights (2010), *Inhuman treatment of persons with disabilities in institutions*, Human Rights Comment, available at: [http://commissioner.cws.coe.int/tiki-view\\_blog\\_post.php?postId=93](http://commissioner.cws.coe.int/tiki-view_blog_post.php?postId=93).

25 Council of Europe, Commissioner for Human Rights (2012), *Government leaders distort justice when they interfere in individual court cases*, Human Rights Comment, available at: [http://commissioner.cws.coe.int/tiki-view\\_blog\\_post.php?postId=207](http://commissioner.cws.coe.int/tiki-view_blog_post.php?postId=207).

26 European Commission (2008c).

27 European Commission (2010a).

28 WHO and World Bank (2011).

29 See: [www.inclusion-europe.org/en/about-us](http://www.inclusion-europe.org/en/about-us).

30 See: [www.inclusion-europe.org/en/self-advocacy](http://www.inclusion-europe.org/en/self-advocacy).

31 See: [www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/WhatIsLearningDisability.aspx](http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/WhatIsLearningDisability.aspx).

32 See: [www.wnusp.net/](http://www.wnusp.net/).

33 See: [www.internationaldisabilityalliance.org/en](http://www.internationaldisabilityalliance.org/en).

34 United Nations Committee on the Rights of Persons with Disabilities (2011), para. 8.

35 See: [www.enusp.org](http://www.enusp.org).

36 See, for example, Beresford, P. (2000), pp. 167-172.





The report reflecting these differences is divided into two main chapters presenting findings relating to persons with intellectual disabilities and findings relating to persons with mental health problems. Each chapter is divided into five main sections dealing with living arrangements, daily living, support options, participation in the community and barriers to inclusion and participation.

## Choice of countries

The fieldwork research was carried out in nine EU Member States (Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom) reflecting a range of geographical regions within the EU and a variety of disability and welfare policy regimes, as well as different approaches to deinstitutionalisation and guardianship. For instance, whereas in Sweden the deinstitutionalisation programme<sup>37</sup> has replaced large residential institutions with group homes with no more than six residents, large-scale residential institutions still exist in several EU Member States, such as Bulgaria, Hungary, Latvia and Romania. The provision of personal assistance schemes to support daily living also varies from minimal such provisions, for instance in Greece, to strong entitlements, for instance in Sweden. There is also considerable variation in the emphasis given to choice and control over budgets given to persons with disabilities to purchase support, also known as direct payments, with Germany and the United Kingdom having comparatively strong measures in place.

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37 Sweden, Law Concerning Support and Service for Certain Groups of Disabled People (*Lag om stöd till vissa funktionshindrade*) (LSS, 1993) SFS 1993:387 and the Law Concerning Compensation for Assistance (*Lag om assistansersättning*) (LASS, 1993) SFS 1993:389.



# 1

## Experiences of persons with intellectual disabilities



This chapter explores some of the complexities people with intellectual disabilities experience in connection with living independently and being included in the mainstream community.

A total of 105 people with intellectual disabilities were interviewed (see Table 1.1 below). The highest proportion of respondents (64 out of 105) was between 26- and 45-years old and the majority of the interviewees were men (58 v. 47 women). The largest proportion of interviewees came from Greece (20), followed by the United Kingdom (14), while the smallest proportion came from Hungary (9). In Bulgaria, France, Germany and Romania, ten respondents were interviewed. More details of the sample composition at national level can be found in Annex 1.

### 1.1. Living arrangements

All research respondents lived at the time of the interviews in the community, either: alone or with a partner or friend; with their parents or other relatives; or they lived in group homes. Their experiences varied widely. A small number of respondents from some of the EU Member States owned their own homes. The respondents' level of satisfaction with their living arrangements depended largely on their previous living conditions. People who had recently moved out of institutions were pleased with the group homes they had moved into. Even if they had to share most of the facilities such as the bedrooms and day rooms with other people, the group homes were still a great improvement over the institutions. No respondents were living

Table 1.1: Respondents with intellectual disabilities, by country, age and gender

Country	Number of interviewees	Men					Women				
		Age < 25	26-45	46-65	>66	Total	Age < 25	26-45	46-65	>66	Total
BG	10	4	2	0	0	6	1	3	0	0	4
DE	10	1	3	1	0	5	0	4	1	0	5
EL	20	3	5	4	0	12	0	5	2	1	8
FR	10	1	5	0	0	6	0	3	1	0	4
HU	9	2	2	1	0	5	0	4	0	0	4
LV	11	1	6	0	0	7	0	3	1	0	4
RO	10	1	2	0	0	3	5	2	0	0	7
SE	11	1	3	2	0	6	0	4	1	0	5
UK	14	0	4	3	1	8	1	4	1	0	6
<b>Total</b>	<b>105</b>					<b>58</b>					<b>47</b>

Source: FRA, 2011

in institutions at the time of the interviews but many had prior experiences of living in institutions as children and/or as adults.

## Living alone, with a partner or with a friend

Few research respondents lived alone or with a partner or friend. In Bulgaria, Greece, Hungary, Latvia and Romania, for instance, none of the respondents lived alone. In France and the United Kingdom, in contrast, the majority lived on their own in rented flats. Overall, respondents expressed a general desire for more autonomy over their living arrangements:

*"[...] see, I want my own key and my own front door"*

*(Man, 34, Latvia)*

They wanted a system in which:

*"[...] you can choose who you want to live with and who helps you."*

*(Man, 39, Germany)*

In Sweden, about half of the respondents lived on their own. The Swedish law on Special Support and Services for Persons with Disabilities (LSS)<sup>38</sup> provides for the right to a place in a group home, an apartment with special services or another specially adapted apartment for individuals deemed to have large or persistent difficulties in managing daily life. In 2009, 83 % of individuals entitled to services under the LSS were people with intellectual disabilities. Under this law, individuals secure property rights over accommodation with certain conditions, including: the accommodation must be of a high quality, sufficiently removed from other such housing arrangements and without any restrictions on movement or association. A woman (32) respondent in Sweden shared her positive experience of the support and choice she had over a place to live: after living with her mother for several years, she moved to her own sheltered apartment, which she had chosen herself and where she was satisfied with the staff that helped her.

Three of the French respondents who lived independently found their flat with the help of their parents or their guardian:

*Interviewer: "Could you decide where to live, where to get a flat [...] if you got money?"*

*Man: "For the flat we had to meet together to see how we were going to do things, because we needed both guardians to get along together."*

*Interviewer: "Did you organise a meeting with the guardians?"*

*Man: "Yes."*

*Interviewer: "Did you do that to choose the flat?"*

*Man: "Yes. That's right. To see how we could move forward together; who should do what."*

*Interviewer: "Did you decide on the place yourselves?"*

*Man: "Yes [...] with my girlfriend. After visiting it, we said: this is very good."*

*(Man, 31, France)*

In Romania, lack of private space and autonomy were issues raised in most interviews. None of the respondents had received any information about their entitlements to social housing; stakeholders stressed that community support services facilitating independent living are urgently needed.

## Living with parents or relatives

Parents and relatives are often a vital source of support for people with intellectual disabilities living outside institutions. Living with parents or relatives can, therefore, be seen as a way of combining accommodation and personal support. Over half of the respondents in the study lived with parents or relatives, with as many as 17 out of 20 Greek respondents living in such arrangements.

*"Currently I live with my grandmother, but I was staying with my mother, with my parents before. But then I moved to my grandma, because my mother was working at the police, in the identity department, so then they could not look after me anymore, because my mum was working, and my dad was working as well, so then I moved to my grandma."*

*(Man, 37, Hungary)*

Stakeholders in Greece stressed the important role of families in terms of the support and care they provide but also pointed to the danger of family members becoming overprotective:

*"Parents think that people with intellectual disabilities are always children and do not let them take any initiative."*

*(Stakeholder, Greece)*

Financial considerations sometimes played a significant role in determining whether respondents lived with their families into adulthood:

<sup>38</sup> Sweden, Law Concerning Support and Service for Certain Groups of Disabled People (LSS, 1993) (*Lag om stöd till vissa funktionshindrade*) SFS 1993:387.

*“Well, my plan is to leave the ‘family nest’ at some point, but I do not really know when. I would like to have my very own life, separate from my parents [...]. [A]t the moment I am thinking of renting a flat, but if I count my monthly income, I do not think I could afford it.”*

*(Woman, 30, Hungary)*

Financial incentives for accommodating relatives with disabilities can also lead family members to try to prevent such persons from leaving home. Stakeholders in Latvia, for instance, argued that some families are preventing people with intellectual disabilities from leaving the family home because their social security benefits are regarded as a source of additional family income. The government representative in the stakeholder focus group in Latvia said that, since the start of the economic recession, families have shown greater interest in keeping relatives with disabilities at home, and waiting lists for places in long-term social care institutions have shrunk considerably. In Greece, one of the stakeholders suggested that there may be a link between the financial incentive to keep children with disabilities within the family home and their loss of legal capacity, because families with children with disabilities receive disability pension only if the child is under guardianship.

## Living in group homes

Group homes are settings catering for a small group of persons that also provide on-site assistance. While there is no commonly accepted definition of a group home, a European Commission funded study identified group homes as “typically 5-6 people living together, though some examples may have up to 10 people resident. In some situations these are provided for people with mild or moderate disabilities but in others they are provided for people with more severe disabilities or complex needs [...]. Staff support varies from visiting or drop-in support to 24-hour cover, depending on the needs of residents.”<sup>39</sup> These settings are referred to as ‘protected homes’ in Bulgaria, ‘serviced apartments’ in Sweden, ‘group apartments’ in Latvia, ‘residential homes’ in Hungary, or ‘protected apartments’ in Greece.

While most persons with disabilities in Sweden live independently, some of those with specific support needs also live in group homes. In Latvia, in contrast, in 2009 there were only 12 group homes for people with intellectual disabilities or mental health problems, for

a total of 168 residents.<sup>40</sup> While Bulgaria is taking steps to make community structures available, NGOs report instances where group homes have been established within the old institutional settings. The Bulgarian Helsinki Committee reports that a number of ‘deinstitutionalised’ people were simply shifted to another area of the same institution.<sup>41</sup>

There were considerable differences in the numbers of respondents living in group homes. All but one of the respondents in Bulgaria and seven of eleven respondents in Latvia lived in such arrangements. In Hungary, Sweden and the United Kingdom, by contrast, only one respondent lived in a group home and, in France, none did.

Respondents pointed to the dichotomy between the protection and independence that group homes offer their residents. One man considered the protection offered by the group home as a safety net:

*“It is nice here [in the group apartment], it is kind of safe, there is security, strangers cannot get in, in that way it is nice.”*

*(Man, 34, Latvia)*

Others, instead, viewed this protective aspect as an unwelcome monitoring measure. A Swedish respondent who had moved to a group home from his parents’ at age 20 said the move had cost him his freedom and the possibility to assume responsibility for his own activities:

*“I got help with finding a service apartment but it only worked so-so because they did not actually listen to how I wanted it to be. They tried to control me kind of. And that did not work. I did not agree to that. They came with a lot of stuff like they wanted to decide how and when we were going to do stuff and it kind of did not feel like I had any say in anything. And I felt like [...] I was always left behind, never listened to, it felt like the other [person] who belonged in the service apartment always came[...] before me.”*

*(Man, 45, Sweden)*

<sup>40</sup> Latvia, Ministry of Welfare (2010) Public annual report of 2009 (*LR Labklājības ministrija, 2009. gada publiskais pārskats*), p. 28; available at: [www.lm.gov.lv/upload/gada\\_parskats/gada\\_parskats\\_09\\_2.pdf](http://www.lm.gov.lv/upload/gada_parskats/gada_parskats_09_2.pdf); Latvia, Ministry of Welfare (2010) Social services and social assistance in town/region in 2009 (*LR Labklājības ministrija, Sociālie pakalpojumi un sociālā palīdzība pilsētā/ novadā 2009. Gadā*), available at: [www.lm.gov.lv/text/1728](http://www.lm.gov.lv/text/1728).

<sup>41</sup> Bulgarian Helsinki Committee (2009) *Needs assessment of the structures involved in the process of deinstitutionalisation of the care of persons with severe mental diseases and mental disabilities*, Monitoring report, August 2008-August 2009, Sofia, available in Bulgarian at: [www.bghelsinki.org/index.php?module=resources&lg=bg&id=0&cat\\_id=19#2009](http://www.bghelsinki.org/index.php?module=resources&lg=bg&id=0&cat_id=19#2009).

<sup>39</sup> Mansell, J., Knapp, M. et al. (2007) p. 9.

Another Swedish man had an ambivalent impression of group homes: on the one hand, he saw them in a positive light:

*“You never need to be alone.”*

(Man, 33, Sweden)

on the other:

*“The staff sometimes interfered in our privacy.”*

(Man, 33, Sweden)

In a similar vein a Greek woman (52) commented on the institutional characteristics that can be found in a group home:

*“No matter what it is called, for me it is an institution.”*

(Woman, 52, Greece)

## Experiences in institutions<sup>42</sup>

All the countries covered by the research had embarked upon ‘deinstitutionalisation’ programmes, but the transition to community living is at different stages and many people with intellectual disabilities still live in institutions. Sweden was one of the first countries in Europe to implement a deinstitutionalisation process, and currently has no institutions for people with intellectual disabilities. Countries such as Bulgaria, Hungary, Latvia and Romania still rely on institutional settings for the provision of care for people with disabilities.<sup>43</sup>

None of the research respondents lived in large social care institutions at the time of the interviews but many had lived in such institutions as children and/or adults, mostly in Bulgaria, Hungary and Latvia. A smaller number of respondents in Germany, Greece and the United Kingdom also reflected on their childhood experiences of institutional life. Respondents said that living in institutional settings left them with little, if any, control over their lives, for instance when they were transferred to other institutions:

*“I was abandoned as a baby in the ‘Mother and child’ home [...]. Then at the age of two they moved me to the home for small children [...]. Then the director and teachers from another home came with cars to bring us to the village [...] where we had to study first grade. But the director told me one day that I would be moved to another special school [...] and they moved me there. After eighth grade I studied in the special boarding school for vocational training [...]. Then I lived in a home for blind people [...]. After that I was moved to a home for men with intellectual disabilities [...]. I was in other homes in the meantime, too, as I did not have another place to live.”*

(Man, 32, Bulgaria)

Even upon reaching adulthood, care takers and the institution’s administrative personnel held in their hands the decisions as to future living arrangements, giving the person concerned little choice or control.

*“[After finishing residential boarding school] then they decide to either send you to a social care institution or find you an apartment if you are capable of living independently. The director makes the decision [...], if the person cannot take care of himself, then he [the director] sends them to a social care institution.”*

(Man, 30, Latvia)

Stakeholders noted that guardianship laws may play a role in restricting the opportunities of people with intellectual disabilities to choose to enter or to leave social care homes. In Bulgaria, for instance, an advocacy organisation said that the majority of people with intellectual disabilities residing in institutions are placed under the guardianship of social workers or directors of the institution in which they live.<sup>44</sup> In Hungary, being declared legally incapable, and therefore placed under plenary guardianship, is considered a way to enhance eligibility for places in institutions, stakeholders argued; thus some families may try to deprive relatives with intellectual disabilities of their legal capacity in order to secure them places in such establishments.<sup>45</sup>

The respondents also noted signs of change that had taken place in institutional facilities over time. Some commented on improved material conditions, others pointed to greater respect for residents’ personal dignity and privacy:

42 Many of the respondents identified diverse forms of residential facilities – including boarding schools, orphanages, small and large community living facilities, and various other forms of residential facilities – as institutions and described how many of these places had institutional characteristics and practices regardless of the number of people living there.

43 For more information on the deinstitutionalisation process in Europe, see Mansell, J., Knapp, M. et al. (2007). See also European Commission (2009).

44 Mental Disability Advocacy Centre (2007) Guardianship and Human Rights in Bulgaria, available at: [www.mdac.info/documents/Bulgaria%20report\\_comprehensive\\_English.pdf](http://www.mdac.info/documents/Bulgaria%20report_comprehensive_English.pdf), p. 113.

45 Verdes, T. and Tóth, M. (2010) *A per tárgya. Gondnokság alá helyezett személyek társadalmi kirekesztődésének mozgásformái a rendszerváltás utáni Magyarországon*, Budapest, ELTE Eötvös Kiadó.





*"[...] right at the beginning there were beatings [...] when I was young [...] that was the discipline [...] not today, let's say, the staff can't do things any more like they did twenty or thirty years ago. [...] They only come in my room when I want them to [...]."*

(Man, 50, Germany)

Respondents who had experienced life both in institutions and in the community spoke of life 'inside' and life 'outside' when they compared the two. Overall, they preferred more autonomy:

*"In a home [and outside], they are two different worlds."*

(Woman, 34, Germany)

*"I prefer to live outside institutions. It is better to live in the community as in this way one can be among people, can find a job, can talk to people, and can laugh with them. But when one lives in an institution one cannot find anything."*

(Woman, 44, Bulgaria)

*"I did not like living together like that – so many people. Not together. Now it's much better. You can live freely, like a human being. [...] When I was a kid I was scared to go out the door and be in public. I was very afraid. But now I am living in the community. Now I am free to go where I need to do my things and I am not scared any more. I feel independent and safe."*

(Man, 34, Latvia)

## 1.2. Daily living

### Education

The most striking finding with regard to education was how many respondents had received no or little education and that the majority who had attended schools were educated in segregated settings. Research has shown that children and youth with intellectual disabilities have the lowest educational attainment among all children with disabilities. Furthermore, they are often educated in segregated settings, as inclusive education is not widely available.<sup>46</sup> In Germany, for instance, according to official sources only 15 % of all children with disabilities attend mainstream public schools and 44 % of pupils in special schools are children and young people with intellectual disabilities.<sup>47</sup> In France, about 52,000 children were educated in mainstream schools, another 50,000 in special classes in mainstream schools and 115,000 in segregated schools.<sup>48</sup> In Latvia, according

to an NGO report, in 2008, 4,586 children with intellectual disabilities studied in special education institutions, and only 931 children attended mainstream schools.<sup>49</sup> In addition, 13.7 % of children with intellectual disabilities had never attended school at all.<sup>50</sup>

In Sweden, special education in segregated schools for pupils with intellectual disabilities is rare. Persons with intellectual disabilities are either included in regular classes in mainstream schools or attend special classes within a mainstream school. In both cases education is provided at a slower pace and the curriculum is appropriately adapted.

Most research respondents had attended a segregated school and only two had university education. The experiences of the respondents differed and they expressed various views concerning education quality and outcomes. Some said they felt little effort had been put into their schooling by education authorities.

*"I finished two [grades]. They gave me sleeping pills at school and I spent most of the time sitting under the desk, I just did not want to study."*

(Man, 36, Latvia)

In Bulgaria, most respondents were placed in vocational schools for young adults with intellectual disabilities and learned skills in sewing, machine processing, cooking, construction or gardening. They still lacked, however, the literacy skills taught in general education curricula.

*"[...] I am illiterate. I feel ashamed of this but it is the truth [...]. I need to pay for my education but to be able to pay I need to have a job and I do not have a job now."*

(Man, 28, Bulgaria)

*"Once you have an intellectual disability you are deprived of the simple right to education and this makes you a cripple till the end of your life [...]. But once you are over 16 no one wants to teach you in general schools if you have a disability."*

(Man, 32, Bulgaria)

Elsewhere, respondents recounted positive educational experiences, highlighting the skills they had developed at special schools:

46 Ebersold, S., Schmitt, M.J. and Priestley, M. (2011).

47 Germany, *Nationaler Bildungsbericht 2010*, Bundestagsdrucksache 17/3400, available at: [www.bildungsbericht.de/daten2010/bb\\_2010.pdf](http://www.bildungsbericht.de/daten2010/bb_2010.pdf).

48 De Lacerda, E., Jägers, C., Michaudon, H., Monteil, C., and Trémoureux, C. (2010) *La scolarisation des enfants et adolescents handicapés*, Note d'information, p. 12, available at: <http://media.education.gouv.fr/file/11/9/5119.pdf>.

49 Erdmane, A., Leimande-Veldmeijere, I., Mucins, R., Veits, U. (2009) *Report on the Implementation of the World Health Organization's Mental Health Declaration and Action Plan in Latvia*, Riga: ZELDA Resource Centre for People with Mental Disability, p. 33, available at: <http://zelda.org.lv/wp-content/uploads/file/REPORT-86lpp-10dec-2.pdf>.

50 Latvian Movement for Independent Living (2010) *Children and Young Persons with Intellectual Disabilities in Latvia*, p. 7-8, available at: [www.lkndz.lv/lv/?n=informativie\\_resursi](http://www.lkndz.lv/lv/?n=informativie_resursi).

*"[Going to a special school] for some people, it is a plus that bears its fruits. [...] I learned to read and write there."*

(Man, France)

*"From the moment I went from the ordinary setting to the protected setting, how to say, for me, it helped [...] there was less pressure, I got along well with my classmates."*

(Man, France)

*"The years I spent at [boarding school] were the best two years of my school life [...] I just felt comfortable. I was learning new skills like washing, cleaning teeth, and then I was doing things that I didn't get a chance to do at my previous schools. Playing sports on grass instead of concrete [...] and because there were only 30-35 of us, you did a lot better than you would have done if you had been in a school of 100 or 150. Because you got to know each other better."*

(Man, 40, United Kingdom)

Some research respondents who were active in self-advocacy groups<sup>51</sup> strongly supported the inclusion of children with intellectual disabilities in mainstream education.

*"First of all, I don't like special schools. They're not a good solution. To separate people just because they happen to have a diagnosis is not right. But we keep fighting here at [self-advocacy organisation] and even I fight for the rights to attend a mainstream school and get the help that you need and to make it so that the education is tailored to the students' needs. That is something I find very important."*

(Man, 45, Sweden)

Some stakeholders suggested, however, that it can be difficult for children with intellectual disabilities to attend mainstream education, either because the schools fail to provide reasonable accommodation due to a lack of financial resources or because of the discriminatory attitudes of school authorities.

*"There is very clear discrimination in education against people with intellectual disabilities. When my son was seven, the schools explained to me that he was uneducable. The teaching materials and programmes were not adapted to the needs of children with intellectual disabilities."*

(Chair of a parents' association, Bulgaria)

<sup>51</sup> In self-advocacy groups people learn to speak up for themselves and the things that are important to them, and support each other in developing and using self-advocacy skills regarding, for example, communication and negotiation.

## Promising practice

### Making education inclusive

ELTE University in **Hungary** partnered with information technology and consulting company International Business Machines (IBM) to create a support system for students with disabilities that would enable them to meet mainstream academic requirements through the help of specialised techniques such as information technology devices and a peer mentor system. The university's social sciences department developed a new equal rights policy which focuses on enhancing accessibility and offers intensive, personally tailored support instead of exemption from exams or the setting of easier assignments. In addition, IBM offers internships to students with disabilities and support infrastructural development on the university's two campuses to make them accessible for persons with disabilities. The programme was launched in 2009 and 20 students, of whom three-quarters have mental health problems and/or intellectual disabilities, have taken part.

The Special Education Centre established by the Speranța Habilitation Foundation in Timișoara, **Romania**, focuses on helping children with intellectual disabilities integrate into mainstream schools. The centre offers support to both families and schools in the mainstreaming process, and works to change society's attitudes towards children with intellectual disabilities. The foundation also acts as a resource centre for mainstream schools, providing information and counselling for teachers, parents of children with disabilities and the children's schoolmates; offering support in the classroom through a support teacher; and developing and distributing adapted curricula.

For more information on the project in Hungary, see: [www.elte.hu/file/yves\\_beszed.doc](http://www.elte.hu/file/yves_beszed.doc) and [www.mastertema.eu/studentlife/special](http://www.mastertema.eu/studentlife/special); and in Romania, see: [www.eenet.org.uk/resources/docs/speranta.php](http://www.eenet.org.uk/resources/docs/speranta.php)

## Employment

The Equality Employment Directive<sup>52</sup> prohibits direct and indirect discrimination, as well as harassment and any instruction to discriminate on grounds of disability, religion and belief, age, and sexual orientation. It covers the fields of employment and occupation, vocational training and membership in employer and employee organisations. It sets out minimum requirements and Member States may provide for a higher level of protection in national legislation. According to Article 5 of the directive employers are required to take appropriate measures to enable persons with disabilities

<sup>52</sup> Council Directive 2000/78/EC, OJ 2000 L 303.





to access, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on employers ('reasonable accommodation').

Nevertheless, there is evidence that persons with intellectual disabilities have limited employment opportunities. For instance, according to official sources<sup>53</sup> in Sweden only 10 % of people with intellectual disabilities are in employment. In the United Kingdom,<sup>54</sup> only 6.4 % of adults with moderate to severe intellectual disabilities who are known to social services departments are in paid employment, while in Romania the figure is only 1 %.<sup>55</sup> Furthermore, in some countries persons with intellectual disabilities can be considered as unfit to work on the basis of their medical diagnosis without an evaluation of their individual skills.

Some EU Member States have taken measures to improve the situation. Sweden has, for instance, developed a range of special services to assist in labour market integration through work internships, subsidised positions, sheltered employment in the public sector and special introductory and educational support, including a support person. In 2009, between 22 % and 23 % of new respondents in the special introductory and educational support scheme were people with intellectual disabilities and people with mental health problems, according to official sources.<sup>56</sup> Research respondents saw work as an important part of everyday life, a value in itself, a way of proving one's worth and means to actively contribute to and engage with society. They often expressed the wish to engage in valued and productive activities:

*"I feel bored staying here in the home. I want to work. And I know that I will work from July to December this year at the place where the others work temporarily now. I want to work to earn money. It would be more interesting to work."*

(Woman, 44, Bulgaria)

*"If I worked, I would like to be an operator at a phone centre. I enjoy talking with people. Not with people who live or work here [at the day care centre]. [...] with people in the outside world."*

(Woman, 52, Greece)

However, many respondents spoke of the obstacles they encountered when looking for work and at work, linked mainly to negative attitudes and direct or indirect discrimination.

*"It is not easy to know if you should be honest and tell people about your impairments – or if you should hide them. In both cases you might end up being unfairly treated. If you don't tell – that's wrong. If you tell they will discover your shortcomings."*

(Man, 42, Sweden)

*"At the beginning it was very hard, they had difficulties in accepting a disabled person in town [...]. Yes, yes, yes [...] I had a harsh foreman [...] he said to me: 'so you've come from [organisation for people with disabilities]. Anyway, disabled people have no place here [name of town]. This is of no use'. I was shocked then [...] in fact it was psychological harassment. He had difficulty working with a disabled person. And then I met with another foreman, who takes care of me."*

(Man, 42, France)

Social security legislation requirements can also affect persons with intellectual disabilities. A respondent in Sweden, for instance, spoke about how his special education certificate influenced the employment choices offered to him:

*"We are discriminated against when it comes to work; we can't register with the Public Employment Office and expect to get a job, because we have marks from special education [special education certificates] and then you are offered daily activities instead of a regular job."*

(Man, 23, Sweden)

The mother of a man with intellectual disabilities in Bulgaria shared a similar problem:

*"I have to say that the medical assessment commission prohibited my son from working, even though he is able to do a lot of things, especially those that require physical labour. I initiated a case before the National Labour Medical Assessment Commission to challenge the assessment. So even if he applies for a job and the employer hires him, that employer would be breaking the law. He was assessed as having 98 % reduced working capacity and was deprived of the right to an assistant."*

(Mother of man, 22, Bulgaria)

53 Sweden, Public Employment Service, (*Arbetsförmedlingen/ Statistiska centralbyrån*) (2009) *Funktionshindrades situation på arbetsmarknaden 4:e kvartalet 2008*.

54 United Kingdom, Office for Disability Issues (not dated) *Jobs for People with Learning Disabilities*, available at: [www.officefordisability.gov.uk/odi-projects/jobs-for-people-with-learning-disabilities.php](http://www.officefordisability.gov.uk/odi-projects/jobs-for-people-with-learning-disabilities.php).

55 Romania, National Authority for Persons with a Handicap (NAPH) (2011), *Statistical Data*, 30 June 2011, Q1.

56 Sweden, Public Employment Service (*Arbetsförmedlingen*) (2010) *Arbetsmarknadspolitiska program. Årsrapport 2009*. Ure 2010:1, p. 122.

## Promising practice

### Assisting with the job search

Programmes and initiatives to support persons with intellectual disabilities to find employment are in place in many EU Member States. Some are national-level policies designed and implemented by governments or private companies, while others are organised by civil society organisations and may be focused on specific towns or cities.

The **Romanian** Ministry of Labour, Family and Social Protection issued Order No.1/2011 in January 2011 creating a new occupation called 'Specialist in supported employment (job coach)' to complete the Romanian Classification of Occupations. This role consists of assisting, analysing and proposing measures for persons with disabilities who are seeking employment, and providing support for activities in the workplace. The supermarket chain ICA in **Sweden** launched a campaign in 2009 called 'We can do more!', with the aim of employing between 500 and 1,000 persons with intellectual disabilities within three years. By the end of 2011, more than 900 persons with intellectual disabilities had been recruited.

In **Latvia**, the NGO Saule runs a Supported Employment Bureau, which provides assistance to persons with intellectual disabilities in finding jobs and, if necessary, provides coaching and further support once the person is working. The system has helped eight clients with intellectual disabilities to stay in jobs for long periods of between three and eight years.

*For more information on the initiative in Romania, see: <http://reports.ica.se/ar2011en/Start/Sustainability/ICA+in+the+community/Important+events+in+2011> and [www.ica.se/Global/Om%20ICA/Pdf/ICA\\_GRI\\_\(E\)\\_110308.pdf](http://www.ica.se/Global/Om%20ICA/Pdf/ICA_GRI_(E)_110308.pdf); and in Latvia, see: <http://saule-rb.lv/info.php?sadala=4&asadala=5>*

## Day centres

Many respondents said that when not in full-time paid employment or education they spend their time in day centres. Most respondents in Greece attended day services which they referred to as 'schools'. In most cases, parents made the choice of day service. Still, most Greek respondents liked their 'schools':

*"It is nice here. I am having a good time. I even work; I weave [...] I want to come. I prefer it to staying at home all the time. I take music lessons as well."*

*(Man, Greece)*

Stakeholders in Greece underlined the importance of day services for children as a means of providing some autonomy and self-determination for those living

with their parents and with limited contacts outside the family:

*"Children who are at specialised centres have some way out; they leave the home for several hours and this is good for them. There they have a psychologist, a social worker, a trainer; they have something to do."*

*(Stakeholder, Greece)*

In Romania, all respondents mentioned the important role of day care centres in ensuring interaction and company, as well as in making information that concerns them accessible. They stressed, however, that access to such facilities depends on financial resources and the availability and willingness of family members with whom they live to accompany them.

In Latvia, a man now attends a day centre he learned about from a television programme. This was his first opportunity to spend his time in any meaningful way:

*"I wandered around the city [...] or stayed at home between four walls."*

*(Man, 23, Latvia)*

Another man wanted to attend the day centre to spend more time with people and:

*"To learn something. [...] I come around 8:30, eat breakfast and lunch then after lunch I go to work."*

*(Man, 38, Latvia)*

However, respondents also raised concerns about day centres, arguing that such settings offer little scope for integration. Respondents in Hungary, for instance, suggested that active social involvement is offered mainly among persons with disabilities who attend other day centres.

Some stakeholders also raised issues related to the quality of care provided in day centres and their ability to meet the needs of all interested persons. They suggested, for instance, that staff may not be sufficiently trained, or that the services may be inappropriate for some people.

*"I decided to run a day-care centre by myself as the experience I had with my daughter attending other day-care centres showed that her condition worsened and she got epilepsy as a result."*

*(Mother of a young adult with intellectual disabilities, Bulgaria)*



*“The young adults who come into our centre have very different conditions and needs and we know that it is not appropriate for all of them to come to our centre. Some have much greater potential but have no other place to develop it. Others need much more support than what we can offer. However, we are at least one place where these adults can come and talk, learn and make friends. Otherwise they would stay at home watching TV or playing on their computers on their own.”*

(Director of day centre, Bulgaria)

## Forming a family

People with intellectual disabilities were in the past often prevented from having children.<sup>57</sup> Obstacles continue to prevent people with disabilities from forming a family. In Latvia, for instance, municipal regulations<sup>58</sup> in Riga do not permit people with intellectual disabilities in community-based group homes to continue living there if they bear a child or start a family life. In the United Kingdom, the seventh Joint Parliamentary Committee on Human Rights report<sup>59</sup> noted that according to research the children of people with learning disabilities are more likely to be removed from their parents' care than the children of people who do not have learning disabilities. Research suggests that this happens in around 50 % of cases involving a parent with an intellectual disability. In France, on the other hand, a 2004 survey<sup>60</sup> reported 144 'Support service for social life' (*Services d'accompagnement à la vie sociale*, SAVS) in 61 regions supporting 683 families with at least one parent with an intellectual disability.<sup>61</sup>

Three respondents in Sweden had established families as adults, with two marrying partners who also had intellectual disabilities. One respondent was a parent, but the child lived with the mother. He was not provided with enough support, he said, to see his child as often as he would like. In France, one male respondent lived with his partner and their son, and two others had children but did not live with them. Few of the respondents with

intellectual disabilities had any experience of having or of taking care of children. Some of these experiences, however, concerned their children being taken into care and were negative:

*“After my husband died we moved to live at my grandmother's house. [She] took care of my son and me. But when she died my uncle decided to place me in a home and this is why they placed my son in a childcare home too.”*

(Woman, 44, Bulgaria)

Three respondents in the United Kingdom reported their young children had been taken into care and they were, therefore, mistrustful of social services.

*“I don't trust social services. If you are a parent with learning disabilities, they think you are not able to look after your kids [...]. They should put the support in at the beginning. We've been doing this training and we've been explaining that to them for years.”*

(Man, 38, United Kingdom)

Stakeholders in Greece said that carers and family members were concerned about the responses they should give to people with disabilities on the difficult issues of sexuality and marriage.

*“When a child with intellectual disabilities asks why he/she never went to school together with his/her sisters and brothers or cousins, and when another says that it is time to get married. What do parents say then? What can be the answer?”*

(Stakeholder, Greece)

Parents and guardians play a significant role in shaping opportunities to establish and maintain relationships. A man in the United Kingdom described how his plans to marry had met with parental opposition, resulting in the break-up of the relationship and his decision to move to a new area:

*“Her dad really didn't want the wedding to go ahead. He was really against it. So he told me mum in a letter what he was wanting. And what he was prepared to do. I think he wanted complete control, he did. [...] I had to call the whole thing off. I can see it now. She threw the ring at me, she did. We went our separate ways. Her family didn't tell her any of what I knew and all that, so she was a bit confused. She didn't know about the letter. She didn't give me a chance to explain.”*

(Man, 39, United Kingdom)

Other respondents spoke about family support in forming relationships:

57 Compere, J.M. (2010) *Parentalité : « L'art d'être parent »*, L'Entente, 2<sup>ème</sup> trimestre 2010, 17<sup>ème</sup> année, n° 66.

58 Latvia, Riga City Council (2007), Binding Rules No. 96, Procedure of Receiving and Funding of Social Services, provided by Riga City Council (*Rīgas domes saistošie noteikumi Nr.96, Rīgas pilsētas pašvaldības sniegto sociālo pakalpojumu saņemšanas un samaksas kārtība*), 11 December 2007, available at: [www.likumi.lv/doc.php?id=169136](http://www.likumi.lv/doc.php?id=169136).

59 United Kingdom, Joint Committee On Human Rights – Seventh Report, 22 January 2008, available at: [www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/4009.htm#note257](http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/4009.htm#note257).

60 France, Laboratoire de Recherche PADI (2004) *Enquête « Déficience intellectuelle et parentalité »*. Lille : Laboratoire de Recherche Parents Avec une Déficience Intellectuelle (PADI).

61 Helfter, C. (2009) *Une parentalité accompagnée. Actualités Sociales Hebdomadaires*, n° 2631 du 6 novembre 2009, available at: [http://sd-1.archive-host.com/membres/up/129373388838288757/Parentatlite\\_39.pdf](http://sd-1.archive-host.com/membres/up/129373388838288757/Parentatlite_39.pdf).

*"I had some relationships previously and it happened a few times that my partner was only after things I had and did not love me for who I am. And of course my family was only trying to protect me. I told my mum about this guy and that he was different. I told her not to judge him before getting to know him. [...] Then my younger brother told me that our parents were not against me but they only love me and want to protect me and want you to be safe with somebody once they will not be around."*

(Woman, 30, Hungary)

### Promising practice

#### Lending families a hand

In some county councils in **Sweden**, health and community care services have started educational programmes to support parents with intellectual disabilities. These programmes include structured, home-based educational activities led by professionals who guide and give feedback to parents. The aim is for the support to reduce stress and increase the self-confidence of parents with intellectual disabilities. So far, around 50 people have taken part in these projects.

For more information, see: [http://english.skl.se/municipalities\\_county\\_councils\\_and\\_regions/activities\\_1](http://english.skl.se/municipalities_county_councils_and_regions/activities_1)

## Access to healthcare

A general concern raised by research respondents was what they perceived as 'lack of understanding' by professional staff, in particular in healthcare. In the stakeholder focus group in Bulgaria, mothers of children with intellectual disabilities said that they felt that healthcare professionals underestimated their children's potential and focused only on their impairments. In France, a respondent suggested that health professionals focused on individuals' impairments, rather than on the individuals themselves:

*"All these people, like psychologists and health professionals, they attempt to help people but they do not try to understand the problems of people, the problem of the individual who is behind the disabilities."*

(Man, 42, France)

In the United Kingdom, respondents spoke of their problems with healthcare staff and services. They said that their physical symptoms, for instance, were not taken seriously by doctors. Medical staff have negative attitudes, they added, or information is inaccessible. They also said that they experienced particular unease when their usual doctor was unavailable and they had to make appointments with doctors and nurses they did not know. Although in some instances people took assistants with them to appointments, this was not felt to be ideal, due to the lack of privacy this

entailed. Respondents said, however, that healthcare services are improving, especially in surgeries where awareness-raising training on intellectual disability had been carried out: two research respondents were in fact involved in training and awareness-raising for general practitioners.

One respondent in Sweden said he had not faced problems in accessing specific healthcare services but complained of a lack of coordination between the different bodies dealing with persons with disabilities.

The FRA conducted fieldwork research focusing specifically on healthcare in regard to multiple discrimination. The results, which relate particularly to people with intellectual disabilities and a migration background, can be found in the upcoming FRA report.<sup>62</sup>

## Leisure

Respondents had little choice or control over their leisure activities. Two young Romanian women said, for instance, that although they wanted to go out, they rarely did, because there was nobody to accompany them and they were afraid to go on their own. They also always needed their parents' permission, they added. Others said that decisions about leisure activities were taken by their family or by social workers, whose presence was sometimes mandatory on social outings.

*"I enjoy theatre and cinema. I go there with my mother. She chooses the film or the play. [If I don't like it] I cannot leave; I have to watch it all. Once I slept."*

(Woman, 32, Greece)

*"I do not know whether we will go again on a trip to the seaside. Maybe if the ladies [social workers] decide we will go [...] the ladies tell us when there are concerts in the city and sometimes they take us there."*

(Woman, 37, Bulgaria)

*"And I had to laugh at the boy that day. He said 'I've got a ticket for a band but I cannot go to hear it'. I said 'How is it you cannot get to hear it?' And he said 'I forgot to get tickets for two staff.' 'How dare they - the two staff should sit outside and you go in!' 'Oh, I cannot do that.' And the two staff were sitting in the cafe next to him when I said it to him. The two staff said [to me] 'you're so cheeky.' 'What?!! I'm only telling the truth - what I think. If I was going to go and you two were coming with me, I'd tell you to go sit outside and go and take a walk.' What do you mean go take a walk?' 'Go on, clear off!' "*

(Man, 63, United Kingdom)

Social and leisure activities are often organised in isolation and with little interaction with the mainstream

<sup>62</sup> See [http://fra.europa.eu/fraWebsite/research/projects/proj\\_multiplediscriminationhealthcare\\_en.htm](http://fra.europa.eu/fraWebsite/research/projects/proj_multiplediscriminationhealthcare_en.htm).





society, respondents say. Hungarian interviewees complained that their cultural and leisure activities happened mostly ‘behind closed doors’. When they talked about holidays, they emphasised that every year they go to the same place with the same people. Similarly, when they attended sporting events, it was always with the clients of a partner institution. Respondents in Germany said that leisure activities take place, at best, with other people with disabilities or with care professionals. Social isolation was seen as something undesirable by the stakeholders in Greece, who argued for more social interaction:

*“There should be specific emphasis on the socialisation of people with intellectual disabilities. To be in the position to do things that everyone does, for instance, to go to a bar, when everyone else is there.”*

(Stakeholder, Greece)

Another important aspect of participating in cultural and leisure activities is the possibility to travel independently, but most respondents had experienced difficulties.

*“They showed us how to use the trolleybuses here but we can’t travel alone without an assistant. [...] They do not allow us to go alone in the city as they are responsible for us and they are afraid something bad can happen to us.”*

(Woman, 44, Bulgaria)

Respondents in Sweden commented that the transport provided them was cumbersome and did not give them equal opportunities to be mobile:

*“One needs to order the transport many hours beforehand and one cannot decide the route taken by the car or minibus because you don’t know where the co-passengers are going.”*

(Man, 23, Sweden)

### 1.3. Support for daily living

In order to participate in the daily life activities described in the section above, persons with disabilities often require support. Support options can turn participation in the life of community on an equal basis with others into something particularly meaningful. If the support operates without the choice and control of the persons receiving it, however, it can curtail freedom. This section examines two options in some detail, namely the provision of a contact person or personal assistant and person-centred support options. The information provided in this section, however, may have changed as EU Member States are reviewing their relevant legislation and policies to ensure compliance with the CRPD.

## Personal assistance

Sweden is the only country of the nine covered in the research that has developed legal provisions on the right to living arrangements and support (Law on Special Support and Services for Persons with Disabilities, LSS).<sup>63</sup> The aim of this support scheme is to give people with intellectual disabilities more freedom to participate in mainstream daily activities and thereby to counteract their isolation. Under the LSS, persons with disabilities can benefit from one or more of the following services: personal assistance, companion services, contact person (support person), relief service in the home, short-term minding of school children over 12, short stay away from home (respite care), group homes for children and adults, daily activities, counselling and other personal support.

The roles of contact person and personal assistant merit particular attention. Individuals awarded this type of help have the right to employ the assistant of their choice or to select the assistant, if they prefer a municipality to be the formal employer. The disabled person can also choose to have the assistance arranged through a user collective or a private provider. In addition, the person has the right to decide what kind of help the assistant should give and in what way. All 10 respondents in Sweden had access to specialised support services to facilitate independent living. Three of them had a contact person and positive experiences.

One woman said of her contact person, a middle-aged woman:

*“She is like my friend, I don’t think very much about not having friends of my own age.”*

(Woman, 29, Sweden)

Her contact person was appointed by the LSS-caseworker, but the respondent was first given the opportunity to meet the candidate and give her opinion before the appointment was finalised. Another Swedish interviewee, aged 45, has had his contact person for the last ten years. They meet every second week and go to the café, cinema and sports events. The man said that he was very pleased with how things were working out.

There are still practical problems due, arguably, to the structure of the welfare system. To help people with intellectual disabilities to overcome such difficulties, the law governing social support provides persons with the right to an individual plan which specifies the division of labour between the different agencies concerned and when and in what way their different tasks are to be accomplished.

<sup>63</sup> Sweden, Law Concerning Support and Service for Certain Groups of Disabled People (*Lag om stöd till vissa funktionshindrade*) (LSS, 1993) SFS 1993:387.

In the other countries researched various policies and programmes are in place to enable persons with disabilities to live independently. In Latvia, for instance, the Disability Law promotes community living and includes a right to a personal assistant.<sup>64</sup> None of the research respondents in Latvia had a personal assistant, which at the time was available only to persons with visual impairments and then for only 10 hours per week. It is foreseen that as of 2013, however, people with other impairments will also be able to benefit from personal assistance for up to 40 hours per week. Bulgaria has also introduced legislation on personal assistance in the form of the Social Assistance Act.<sup>65</sup> The Regulations for the Implementation of the Social Assistance Act, adopted in June 2010, entitle persons with mental health problems or intellectual disabilities (assessed with at least 71 % reduced labour capacity) to an assistant.<sup>66</sup> Such assistance is limited to 10 hours per year.

Existing legal provisions related to personal assistance are in some cases under review. In Romania, for instance, under Law 448/2006 people with severe disabilities, as assessed through social and psycho-medical evaluation, have the right to a personal assistant.<sup>67</sup> An amendment to this law in 2010 stipulated that people with a severe degree of disability will no longer be entitled to a 'measure of special protection', in other words a personal assistant.<sup>68</sup> Instead, they receive a monthly allowance from the city council. Stakeholders commented that, as a result, many people with disabilities had 'dismissed' their personal assistants, often family members, who had received this allowance as compensation but had not declared it as taxable income.

Programmes in France and Greece provide mainly domestic assistance. In Greece, municipalities offer a social welfare programme named 'Help at Home' designed specifically to help the elderly and people with disabilities living alone.<sup>69</sup> None of the research respondents in Greece commented on the choice and control this programme afforded them in their daily lives. In France, support for meaningful community participation is provided by the Support Services for Social Life (*Services d'accompagnement à la vie sociale*, SAVS) and the Medical-social Support Services for Disabled Adults (*Services d'accompagnement médico-social pour adultes handicapés*, SAMSAH). These services help

people with disabilities to manage daily living activities, such as housecleaning, shopping and cooking, and to handle administrative tasks.

## Person-centred support

EU Member States, such as Germany and the United Kingdom, continue to evolve models of 'self-directed' or 'person-centred support' through mainly 'direct payments' and 'personal budgets'.

In Germany, personal budgets have been legally possible since 2001 and a legal right since 2008. Under this system, benefits are paid as sums of money or vouchers, which can be used by the claimant as they see fit. By 2009 around 10,000 recipients had used this form of benefit, according to official data.<sup>70</sup> An evaluation conducted as part of the federal Multi-provider Personal Budget Pilot Project (*Modellprojekte 'Trägerübergreifendes Persönliches Budget'* (2004-2007)) found that 31 % of budget recipients (within the project (from a sample of 845 respondents) were people with intellectual disabilities (the percentage of people with mental health problems was 41 %).<sup>71</sup>

Research respondents in Germany who had access to specialised support services to facilitate independent living spoke of the positive impact these personal budgets had on the power relationships between them and those who supported them:

*"In the employer model [personal budget], I hold perfectly normal job interviews."*

(Woman, 32, Germany)

*"The employer model gives me more quality of life. [...] This budget enables me to build my life up all over again."*

(Woman, 49, Germany)

Stakeholders in Germany also highlighted that personal budgets are an invaluable form of support enabling people with intellectual disabilities to achieve greater self-determination and self-esteem.

In the United Kingdom, direct payments became legal with the passing of the NHS and Community Care (Direct Payments) Act in 1996. While offering direct payments became mandatory for local authorities in 2003 in

64 Latvia, Disability law (*Invaliditātes likums*) of 20 May 2010, Section 1(1), available at: [www.likumi.lv/doc.php?id=211494](http://www.likumi.lv/doc.php?id=211494).

65 Bulgaria, Social Assistance Act, State Gazette, No. 56 dated 19 May 1998.

66 Bulgaria, Regulations for Implementation of Social Assistance Act, 1 June 2010, Article 53a.

67 Romania, Law No. 448/2006 concerning the protection and promotion of the rights of persons with disabilities, republished in the Official Journal Part I, No. 1, 3 January 2008.

68 Romanian Government Ordinance No. 84/2010 amending Law No. 448/2006 on the Protection of Handicapped People.

69 Greece, Law 5814/1997.

70 Deutscher Bundestag (2009) *Bericht der Bundesregierung über die Lage behinderter Menschen und die Entwicklung ihrer Teilhabe*, p. 6, available at: <http://dip21.bundestag.de/dip21/btd/16/138/1613829.pdf>.

71 Metzler, H., Meyer, T., Rauscher, C., Schäfers, M. and Wansing, G. (2007) *Begleitung und Auswertung der Erprobung trägerübergreifender Persönlicher Budgets – Wissenschaftliche Begleitforschung der Modellprojekte „Trägerübergreifendes Persönliches Budget“*, Tübingen, p. 82, available at: [www.bmas.de/portal/23072/property=pdf/f366\\_\\_forschungsbericht.pdf](http://www.bmas.de/portal/23072/property=pdf/f366__forschungsbericht.pdf).



England and Scotland and in 2004 in Wales and Northern Ireland, the law initially stipulated that applicants must be 'willing and able' to manage the process to be eligible. This requirement was removed in 2009 in England<sup>72</sup> and in 2011 in Northern Ireland, opening up the possibility for a third party to directly receive and manage the payments.<sup>73</sup> Recipients of direct payments may decide who to employ, the hours they work and the tasks they carry out. Additionally, the recipient may, if he or she wishes, take all or part of the benefit as an allocation in kind, in other words as a service provided by an organisation, rather than in money.

Take-up of direct payments and personal budgets (a modified form of direct payments) by people with intellectual disabilities has been low in comparison with people with physical disabilities. The number of people receiving direct payments also remains small in comparison with numbers living in residential care and those receiving community-based services.<sup>74</sup> Nevertheless, according to NGO research, take-up increased from 60 people in 2006 with intellectual disabilities reported to them as having personal budget to some 30,000 across 75 local authority areas at the end of 2009.<sup>75</sup>

One respondent who received direct payments said that she used it to employ workers from an agency, which also dealt with the related administrative arrangements. Although in the main the same people visited each week, this was not guaranteed and she did not point out particular benefits to the arrangement compared with others. Nevertheless, it appeared that she did have some control over who provided assistance: she said that one assistant who had stolen money from her was not resent.

72 United Kingdom (England), Health and Social Care Act (2008).

73 United Kingdom, Department for Children, Schools and Families (2009) *Guidance on Direct Payments for Community Care, Services for Carers and Children's Services* London: Department of Health, available at: [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_121131.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121131.pdf).

74 United Kingdom, NHS Information Centre for Health and Social Care (2009) *Community Care Statistics 2008-09: Social Services Activity Report, England*, available at: [www.ic.nhs.uk/webfiles/publications/Social%20Care/socialcarepubs280410/Community%20Care%20Statistics%20Social%20Services%20Activity%20Report%20England%20-%202008-09%20FINAL2.pdf](http://www.ic.nhs.uk/webfiles/publications/Social%20Care/socialcarepubs280410/Community%20Care%20Statistics%20Social%20Services%20Activity%20Report%20England%20-%202008-09%20FINAL2.pdf).

75 Tyson, A., Brewis, R., Crosby, N., Hatton, C., Stansfield, J., Tomlinson, C., Waters, J., and Wood, A. (2010) *A Report on In Control's Third Phase*, available at: [www.in-control.org.uk/media/55999/in%20control%20third%20phase%20report%20.pdf](http://www.in-control.org.uk/media/55999/in%20control%20third%20phase%20report%20.pdf).

## Promising practice

### Supporting community living

In the **United Kingdom**, KeyRing has set up a series of networks to support people with intellectual disabilities to live in the community. Each network is made up of 10 people living close to one another: nine who live in their own homes but need support, and one Community Living Volunteer. The aim of the networks is for the members to support and assist each other with daily living skills and activities, with the volunteer seeing members regularly and helping the group to work together. The volunteer also supports other members of the network to explore events taking place locally and to get involved in them. Paid Community Support Workers and Supported Living Managers can provide additional support services if required.

For more information, see: <http://www.keyring.org/home>

## 1.4. Participation in the community

Participation and inclusion in community life is fundamental to independent living. This section will address the experiences of people with intellectual disabilities on two key issues, namely establishing a voice in public and political life and participating in the self-advocacy movement.

### Participation in public and political life

The FRA report on the right to political participation showed that in most EU Member States persons with intellectual disabilities deprived of their legal capacity, were in consequence also automatically denied their right to vote.<sup>76</sup> Of the nine countries covered by the fieldwork research persons with intellectual disabilities maintain the right to vote regardless of legal capacity solely in Sweden and the United Kingdom. In Hungary and France, a judge decides on the exercise of the right to vote on a case-by-case basis.

A milestone development in this regard is the Council of Europe Committee of Ministers recommendation of 16 November 2011 on the participation of persons with disabilities in political and public life, which states that "all persons with disabilities, whether they have physical, sensory, or intellectual impairments, mental health problems or chronic illnesses, have the right to vote on the same basis as other citizens, and should not be deprived of this right by any law limiting their legal capacity, by any judicial or other decision or by any

76 FRA (2010).

other measure based on their disability, cognitive functioning or perceived capacity".<sup>77</sup> Subsequently, the European Commission for Democracy through Law (Venice Commission) amended its interpretation of its Code of Good Practice in Electoral Matters to state that people with disabilities should "be able to exercise their right to vote and participate in political and public life as elected representatives on an equal basis with other citizens".<sup>78</sup>

Evidence from the interviews suggests that participation in public and political life was closely connected to awareness and accessibility of the electoral process. Respondents in Latvia said they had voted in elections and received information from booklets and newspapers. None of them recalled, however, that anyone had helped them to understand more about the election results or party platforms. Other respondents were often not aware of the reasons for their disenfranchisement.

*"My stepfather arranged it this way so I can't vote and I do not even get called up for military service."*

(Man, 37, Hungary)

Some respondents in Germany and the United Kingdom commented on the right to stand for elections and on the absence of people with intellectual disabilities in parliament.

*"We need more people with learning disabilities in Parliament to change the laws. And you could have people with learning difficulties being in the House of Lords. [...] So more people with learning difficulties as MPs (Members of Parliament) and MEPs (Members of the European Parliament)."*

(Man, 53, United Kingdom)

*"That there's a place in politics for disabled people, that people have a chance to get involved in politics. [...] I think a quota would be good [...] because they'd be more in the public eye."*

(Woman, 49, Germany)

Respondents also noted the need for greater consultation and participation of persons with disabilities and their representative organisations in policy making.

*"People at the ministries and authorities should talk to people like me when they develop legislation and policy. They should ask us what we want and need, and not make our lives more difficult."*

(Man, 32, Bulgaria)

In the United Kingdom, several people with intellectual disabilities were active in campaigning and considered

this to be an effective means of raising the government's awareness about their issues.

*"I don't know about human rights but I'd like the government to listen to us."*

(Woman, 38, United Kingdom)

## Promising practice

### Making elections accessible

EU Member States have undertaken several initiatives to address the accessibility of electoral processes. **Germany** published easy-to-read information about the electoral process. In the **United Kingdom**, Mencap worked with political parties to transform their manifestos into easy-to-read versions, leading to a doubling of the vote of those with intellectual disabilities compared to earlier campaigns.

For more information on Germany, see: [www.sovd-bv.de/file-admin/downloads/wahlhilfe/pdf/bundestagswahl05.pdf](http://www.sovd-bv.de/file-admin/downloads/wahlhilfe/pdf/bundestagswahl05.pdf); and on the United Kingdom, see: [www.mencap.org.uk/campaigns/take-action/get-my-vote](http://www.mencap.org.uk/campaigns/take-action/get-my-vote).

A pan-European project also suggested ways to make elections more accessible, such as the need to: enhance awareness-raising; improve access to polling stations and produce accessible information; train staff; and involve organisations that promote and defend the rights of disabled persons. The project 'Voting for all' was carried out by Inclusion Europe, together with self-advocates from member organisations in Scotland (Enable Scotland), France (Nous Aussi) and the Czech Republic (SPMP).

For more information, see: [www.inclusion-europe.org/images/stories/documents/Project\\_ADAP/index.html](http://www.inclusion-europe.org/images/stories/documents/Project_ADAP/index.html)

## Role of self-advocacy and peer support

Respondents who were more politically engaged, and more aware of their rights, were often members of self-advocacy organisations. In such organisations people with intellectual disabilities discuss among themselves matters that concern them. Self-advocacy organisations and disabled persons organisations (DPOs) are a crucially important way for channelling the needs and views of persons with disabilities, and most importantly, for engaging them actively in an emancipatory political process. Such organisations can also provide important support services and help to increase awareness among persons with intellectual disabilities of their rights and entitlements.

77 Council of Europe, Committee of Ministers (2011), Appendix point 3.

78 European Commission for Democracy through Law (Venice Commission) (2011).





## Promising practice

**Encouraging self-advocacy and peer support**

Overall, peer support organisations aim at increasing self-determination and rights awareness of persons with disabilities. They also help with everyday life situations and access to justice.

In **Germany**, the network People First (*Mensch zuerst*) organises a weekly 'Talk-Hour' (*Sprech-Stunde*) during which persons with intellectual disabilities can contact the organisation and talk to one of its employees or co-workers.<sup>79</sup> The regular session aims to give persons with intellectual disabilities the opportunity to ask questions about issues that are important to them, such as support services, accommodation options and local self-advocacy groups.

People with disabilities have benefitted greatly from peer support organisations' role in providing free legal support. In **Sweden**, the Swedish Disability Federation (*LaSse Brukarstödcent*) is an independent organisation whose counsellors offer advice on legislation and policy. In 2011, a record high of 220 people sought individual advice, generating a further 750 visits, while counsellors also answered queries by phone and post. Most advice (41 % of requests) was sought on economic issues, such as sick pay, funding requests, disability allowance and personal assistance, with other major concerns being personal care, psycho-social support and leisure, including people to accompany persons with intellectual disabilities in social activities.

*For more information on the Network People First, see: [www.people1.de/was\\_machen\\_wir.html](http://www.people1.de/was_machen_wir.html); and on the Swedish Disability Federation, see: [www.lassekoop.se/aerenden-](http://www.lassekoop.se/aerenden-), as well as user support centres (*Brukarstödscentrum*), see [www.brukarstodcentrum.se](http://www.brukarstodcentrum.se)*

Peer support and self-advocacy organisations in the nine Member States covered by the research are at different stages of development and vary in capacity. There are no developed self-advocacy organisations in Bulgaria, while in Greece parents' associations established the majority of organisations offering services to people with intellectual disabilities. In Hungary, Latvia and Romania only a few respondents were either part of a self-assertiveness group themselves or were aware of organisations to which they could turn for support. In the United Kingdom, several respondents participated in the national self-advocacy support organisation of people with intellectual disabilities, People First. People First covers: in Scotland<sup>80</sup> over 90 local groups; in

Northern Ireland, seven;<sup>81</sup> in Wales, 23;<sup>82</sup> and in England, 18. In Sweden, user organisations play a vital role in disseminating information about the abilities and interests of persons with intellectual disabilities.

*"We will show society that we are capable, too. We can do more than people believe. We need to come out!"*

*(Woman, 53, Sweden)*

While peer support organisations provide much needed services and play a vital role in forging the self-determination of persons with disabilities, their funding was generally considered uncertain. At the time of the interviews widespread cuts to public services had hit funding and at least one such organisation had had its funding withdrawn.

*"A lot of them are going under. And that's the problem, we desperately need all different types of advocacy and it needs to be really funded. If it's not funded by grants and government and local authority then we need to make sure that it's self-sufficient."*

*(Man, 45, United Kingdom)*

## 1.5. Barriers to inclusion and participation

This section examines the experiences of respondents on issues which restrict choice and control in the lives of persons with disabilities, such as restrictions of legal capacity, institutional regimes and cultures, difficulties in accessing justice, bullying, harassment and abuse, administrative barriers and financial issues, such as the impact of austerity measures and low income.

### Restrictions of legal capacity

A variety of legislative provisions regulate the deprivation of legal capacity and the appointment of guardians in the countries covered by the research, affecting people's choice and control over their lives.

Around half of the research respondents with intellectual disabilities had been wholly or partially deprived of their legal capacity and placed under different forms of guardianship, including the majority of respondents in Greece. Several respondents gave accounts of how their legal guardians, who are often also family members, had curtailed their opportunities to make choices. The guardians exercised control over financial affairs, but in some cases they also took over other aspects of people's lives, which respondents did not like:

<sup>79</sup> See [www.people1.de/was\\_machen\\_wir.html](http://www.people1.de/was_machen_wir.html).

<sup>80</sup> See: [www.peoplefirstscotland.org/index.html?pid=1](http://www.peoplefirstscotland.org/index.html?pid=1).

<sup>81</sup> See: [www.peoplefirstltd.com/members-northern-ireland.php](http://www.peoplefirstltd.com/members-northern-ireland.php).

<sup>82</sup> See: [www.allwalespeople1st.co.uk/news.asp](http://www.allwalespeople1st.co.uk/news.asp).

*“My mum is my guardian and I can’t say ‘no’ to her [...] If she wants me she can phone up the house. And the house phones her. Everything is controlled by her. And I can’t breathe. Because she’s there – in my face. In this. In that. And you know she’s everywhere. And I’ve tried to [...] I know she’s my mum but [...] I’ve tried to move away from her slowly but it’s not working.”*

*(Woman, 27, United Kingdom)*

*“If I really fancy something then I ask my mum and she will tell me whether I can buy it or not. [...] How can I say [...] she is my guardian so therefore I always have to ask her about everything. [...] I always discuss everything with her – just to be on the safe side.”*

*(Man, 37, Hungary)*

A Swedish man explained that, because he had mishandled some of his bills, staff in his group home had, without his consent, successfully applied for him to be placed under guardianship eight years ago, which he had found upsetting. When asked what the guardian managed, he said:

*“For the moment she pays my bills but she also decides too much about my financial affairs. If I have money I want to make my own decisions.”*

*(Man, 39, Sweden)*

Other respondents who were under supported decision making schemes, rather than plenary guardianship, viewed it as a source of practical support, particularly with paperwork and finances.

*“I’d say, you know, for papers, repayments, all that stuff, I’d say it’s simpler.”*

*(Man, 31, France)*

*“I can’t go out and buy that car or sign up for a contract with a phone provider because the [guardian] has the last word. I trust him and he trusts me. I have always wanted it that way, because I can’t handle real money. I have had a [guardian] for over 10 years, ever since I got the [disability] pension.”*

*(Man, 31, Sweden)*

There was a wide variation among respondents in their awareness levels of the implications of guardianship. When asked if she wanted to vote, one woman under guardianship replied:

*Woman: “I can’t do that anymore.”*

*Interviewer: “Why?”*

*Woman: “I don’t know. I do not receive such letters anymore and I was also told that pensioners [people receiving disability pension] can’t do this anymore.”*

*(Woman, 27, Hungary)*

In contrast, respondents in Hungary who were involved in a self-advocacy organisations had a better awareness of their situation.

*“I am under comprehensive guardianship. [...] Yes. Because of this I cannot vote and we cannot get married either. I am not the only one with these problems, there are many of us. I cannot sign an employment contract; I cannot work so I have many such disadvantages.”*

*(Man, 53, Hungary)*

Finally, respondents in Germany, where all respondents living in group homes had a legal guardian, advised caution in the way guardianship is used:

*“Don’t just give everyone a guardian, check more carefully.”*

*(Woman, 34, Germany)*

## Administrative barriers

Several respondents commented on administrative barriers that limited their choice and control over their place of residence. The barriers are mostly connected to eligibility for benefits or availability of assistance in the new location:

*“I think they are having either a discussion or argument about it, who’s going to take it on. In fact last week a social worker actually came to my flat – from the [local area] social services and asked me lots of questions. He asked me how I would cope if I didn’t have any support and I told them I wouldn’t like that. I’m quite happy the way things are so hopefully it will stay.”*

*(Man, 39, United Kingdom)*

*“It may also happen that you need to make a new application, for instance if the matter concerns housing or daily activities if you want to move. You also need to have a new caseworker which means that you have to tell your story once again.”*

*(Man, 31, Sweden)*



One respondent in Latvia spoke of the administrative obstacles that over the past three years had prevented his wife from moving to live with him: his wife's municipality refused to meet the costs of supporting her if she were to move to her husband's municipality.

*"I just want to live with her. I am just sick of it all. All I want is for her to live with me. Not this situation, where she is there and I am here."*

(Man, 32, Latvia)

On the other hand, a 46-year-old respondent in Latvia said that she and her husband were provided, immediately after their wedding, with a room of their own in their long-term social care centre.

The lack of easy-to-read<sup>83</sup> material or not knowing where and how to get it can prevent people with intellectual disabilities from accessing administrative information and making appropriate choices.

*Interviewer: "Are there areas in your life where you would need some further support, things that you cannot do alone?"*

*Woman: "Well, sorting out my business with the authorities, you know, at the bureaus, that stuff is still not very clear. For example, let's say when you need to sort out your identity card, or whatever."*

(Woman, 30, Hungary)

*"Lots of groups have done something on human rights in easy read [...]. So the material is out there but I think it needs to be advertised more widely."*

(Man, 51, United Kingdom)

In Sweden, respondents and stakeholders spoke of the challenges in interacting with a wide range of welfare agencies, most importantly the public employment service, the social insurance office and the local healthcare centre (primary care), because of differences in their structures and functions. This was attributed to the complex and reportedly<sup>84</sup> fragmented structure of the welfare system.

## Promising practice

### Providing accessible resources

Five out of Latvia's 14 ministries' websites have information in easy-to-read language developed in cooperation with the NGO Agency of Easy-to-read Language (*Vieglās valodas aģentūra*). Important state bodies, such as the Ombudsman, the State Inspectorate for Protection of Children's Rights, the Central Election Commission and the State Employment Agency also provide easy-to-read versions on their websites.

In France, the National Union of Associations of Parents of People with Intellectual Disabilities, and of their Friends (*Union Nationale des Associations de Parents de personnes handicapées mentales et de leurs amis*, UNAPEI) is promoting the general use of a pictogramme « S3A » (*Symbole d'accueil, d'accompagnement et d'accessibilité*), which would allow people with intellectual disabilities to locate the places – such as shops, services and administration offices – which offer assistance and adapted services.<sup>85</sup> The symbol is intended for display on counters, transport, goods or documents.

For more information on UNAPEI, see: [www.unapei.org/le-pictogramme-S3A-symbole-d.html](http://www.unapei.org/le-pictogramme-S3A-symbole-d.html) for the pictogramme « S3A » and the 2010 *Guide pratique de l'accessibilité*, p. 75

## Financial problems

A significant factor determining the range of choice and control persons with disabilities can have over their lives is personal income. According to the Social Situation Observatory report on income distribution and living conditions, on average across the EU as many as 21.6 % of men and 20.6 % of women who report disabilities across all age groups are at risk of poverty, as opposed to 13.5 % and 14.7 %, respectively, of those who do not report disabilities.<sup>86</sup> Lack of financial resources limits the possibilities of persons with disabilities to live independently and be included in the community and makes them more reliant on families and informal support.

83 Everyone has the right to information they can understand in order to be able to take informed decisions. For more information on what constitutes 'easy-to-read' material, see the 'Pathway' project of Inclusion Europe, available at: <http://inclusion-europe.org/pl/icon-display-polityki/self-advocacy-and-accessibility/easy-to-read-project>.

84 Lindqvist, R. (2000) *Att sätta gränser. Organisationer och reformer i arbetsrehabilitering*. Umeå: Boréa.

85 UNAPEI (2011) *Le pictogramme « S3A »: symbole d'accueil, d'accompagnement et d'accessibilité*, available at: [www.unapei.org/le-pictogramme-S3A-symbole-d.html](http://www.unapei.org/le-pictogramme-S3A-symbole-d.html); UNAPEI (2010) *Guide pratique de l'accessibilité*, Paris, Union Nationale des Association de Parents, de personnes handicapées mentales et de leurs amis, p.75.

86 European Commission, Social Situation Observatory – Income distribution and living conditions, Research Note 5 /2011 *The situation of working-age people with disabilities across the EU* p. 15, available at: [www.socialsituation.eu/research-notes/SSO2011%20RN5%20Disability\\_Final.pdf](http://www.socialsituation.eu/research-notes/SSO2011%20RN5%20Disability_Final.pdf).

*“A disabled person can work anywhere and do any job he is capable of, [...] a disabled person cannot live on LVL 75 (€105), completely impossible.”*

*(Man, 30, Latvia)*

*“[...] I have HUF 20,300 (€68) family support, my salary is HUF 47,000 (€157), I could not pay for a flat from that amount of money and besides the rent I also have to pay the bills, I also have to live on something, pay for clothes and all that.”*

*(Woman, 30, Hungary)*

Concern was also expressed that austerity measures taken in the context of the economic crisis can threaten the trend of increasing support for community living and choice and control, by, for instance, restricting eligibility for social support. According to respondents in Bulgaria and Hungary, many families do not have the financial resources to pay fees for integration services provided privately, for instance in day centres.

Financial constraints also had an impact on choice and actual participation in social activities. Respondents in Romania, for instance, claimed that they wanted to have friends and spend more time out, but this depended on whether their family could afford it. Other respondents said that lack of money effectively kept people at home. In the United Kingdom, respondents valued leisure services highly, but for many the cost of participation was a barrier, especially when it was necessary to pay for the costs of support staff.

*“This is the second major lot of cuts that we’ve had in the last four years. So whereas we had quite a few groups doing social activities, there’s barely any now that go out and go to the cinema and go to the theatre or whatever [...]. Doing social things has come to a halt.”*

*(Man, 40, United Kingdom)*

Respondents also noted the effects of the financial cuts on support measures for employment:

*“They told me we are sorry but we have come into hard times and you cannot work here anymore.”*

*(Man, 28, Bulgaria)*

The impact of austerity measures is deeply felt by persons with disabilities. The European Disability Forum, an umbrella organisation for persons with disabilities, developed a Crisis Observatory<sup>87</sup> to collect examples of measures taken by EU Member States, EU institutions and international financial institutions. Respondents, for example in the United Kingdom, argued that cuts in services may jeopardise progress made in the direction of choice and control.

*“[With] all the cutbacks, when the services are not there, and [there’s] not anybody supporting you, they will end up going back to these institutions. And we’ve got to fight to make sure that they do not go backwards.”*

*(Man, 51, United Kingdom)*

## Impact of experiences in institutions

An institution is defined not by its size but primarily by its organisational structure and culture which can, and in practice always does, restrict choice and control. At the time of the research none of the respondents lived in long-term institutions. As such, the recollection of all events relating to such institutions had occurred in the past, many several decades earlier. The experiences described here should, therefore, not be taken to portray the current situation. When recounting such past experiences respondents spoke of lack of privacy, rigidity of daily routines and of power inequalities between staff and patients, which sometimes resulted in acts of violence and abuse.

When recalling their time in long-term care facilities, many respondents focused on the lack of privacy and constant staff surveillance:

*“What bothered me personally was that everything personal is documented. [...] Did she have a male visitor? Did she have a female visitor? What time did the person come? What was the content of the conversation?”*

*(Woman, 49, Germany)*

*“Because it’s like Victorian, ‘put them in there and they’ll be safe’, but you’re not safe. Staff watch you when you’re going for a bath. Especially the men. They come out with things you don’t want to hear [and make vulgar comments about your body].”*

*(Man, 64, United Kingdom)*

*“It was okay for sending letters. But as for the phone, we had to give our mobiles directly to the office for the week as soon as we arrived on Monday morning. We were allowed to check them once or twice a week. If our parents wanted to call us, they needed to dial the number of the IMPro (special school) directly.”*

*(France)*

Respondents also mentioned that rigid schedules restricted their choices.

87 More information is available at: [www.edf-feph.org/Page\\_Generale.asp?DocID=13854&thebloc=13856](http://www.edf-feph.org/Page_Generale.asp?DocID=13854&thebloc=13856).



Interviewer: "Could you come and go as you wanted?"

Woman: "You had to be there at breakfast, dinner and tea and supper. You had to be – you couldn't have a lie-in unless you were ill, could you?"

Man: "You couldn't have a lie-in. No, you couldn't have a lie-in."

Woman: "You weren't allowed to have a key to each other's rooms."

(Married woman and man, 59 and 72, United Kingdom)

"I am supposed to be there at around 7 p.m. as otherwise they would not give me my dinner."

(Man, 21, Bulgaria)

"We have what is served or nothing [...] and this bothers me."

(Woman, 52, Greece)

Respondents said that institutions affected the staff working there as well. They pointed to the social distance imposed between staff and residents, the divisions between 'them' and 'us'. Social workers applied control and punishment, they said.

Man: "It was like they would talk down to you."

Woman: "Didn't like it."

Man: "They would make you call them by their last name. You weren't allowed to use their first name."

Man: "Yes. [...] One of the social workers, I called him John. And he said 'get out'. He said that!"

(Married woman and man, 59 and 72, United Kingdom)

"The home was very structured and if it didn't go according to their wishes, if I didn't follow them to the letter, then there were certain punishments."

(Germany)

Some respondents also described instances of violence and abuse:

"He did not like it when we went to the hill and slid down it, little kids we were. We came back and our pants were wet. He put me on the table and used the clothes iron."

(Man, 36, Latvia)

Respondents also spoke of medication used to control violent behaviour but also simply to make the staff's work easier:

"Say you got in a fight with somebody, well they used to give you the needle to put you to sleep."

(Man, 59, United Kingdom)

"She has power, she gets access to the medication, she is a nurse, she has power. She comes to her shift, she poisons everyone, they sleep all day, she has peace, she can do the jobs she does at home."

(Man, 34, Latvia)

Some of the respondents who had lived in institutions had performed a lot of work while living there, an experience shared, for instance, by three Bulgarian women who used to live together in an institution. All of them recounted that they had helped the staff clean floors, serve food in the canteen, and bathe and change the bed sheets of bedridden residents, commonly without pay, and that this is why staff treated them well. Other respondents, however, had negative experiences with the work they were assigned:

"In the summer we had to do some job every day. The director would line us all up and assign us to groups to do jobs[...]. I said to the nurse that I had a hernia again, and she started criticising those teachers and the director, saying to me 'why do they make you do that? If he [the director] had a hernia, he would not be made to do any heavy work.' But [the director] replied – cut out the laziness, you have to learn about life."

(Man, 30, Latvia)

The experiences of a highly regimented life in an institution can have a long-lasting impact. A woman respondent said that even when her partner is in his own home he still asks for permission to do the simplest things:

"A lot of things that are really normal for me aren't normal for him; he doesn't have to ask if he can have a Coke – it's in his fridge."

(Woman, Germany)

## Bullying, harassment and abuse

Respondents recalled various forms of bullying, harassment and abuse, particularly during periods spent in institutional settings. Most such cases took place at child care institutions such as boarding schools and long-term social care centres. Respondents, however, also spoke about current experiences of mistreatment:

"I often get insulted. I mean, somebody in the street may come up to me and start laughing at me for no reason. And they may also say four letter words to me. I don't want to repeat them."

(Woman, 21, Romania)



*"The other morning when I was going for a walk a man called me a spaz. Then he ran off. That's not very nice, is it?"*

*(Man, 72, United Kingdom)*

*"When I'm on the bus [...] just [like] normal people. When I stand there or sit there perfectly normally, the 'normal' people say: 'Disabled! Disabled!', and it really gets on my nerves. I almost wanted to get up and ask them what they've got against disabled people, but then I didn't have the guts but I will do next time."*

*(Man, 39, Germany)*

Respondents said that bullying and harassment also occurred in their neighbourhoods, where a victim is daily exposed to the perpetrators. In Bulgaria, one respondent recounted how his neighbours filmed him then uploaded the short video to the internet. His mother filed a complaint against the perpetrators, only to discover later that the video had been uploaded to many websites. Stakeholders in Greece noted, in contrast, that the situation at local level tended to improve with other residents becoming more supportive over time, but that, in general, persons with intellectual disabilities still face open ridicule, verbal insults and even physical attacks.

Some respondents also experienced hostility within their own families. A 21-year-old Romanian respondent recalled how her father and sister had verbally abused her.

Respondents also spoke of incidents beyond verbal abuse. In the United Kingdom, respondents recounted incidents in which people made silent phone calls, set a front door on fire, hurled paint and eggs at windows, broke into homes smashing up furniture and, in one instance, launched a physical attack:

*"It was this bloke and his girlfriend. They had sticks and they broke the door down and they just beat me up."*

*(Woman, 45, United Kingdom)*

## Promising practice

### Inquiring into disability-related harassment

The United Kingdom Equality and Human Rights Commission launched an inquiry into public authorities' actions to eliminate disability-related harassment and its causes, finding that for many people with disabilities, harassment is a commonplace experience. The results of the inquiry, published in September 2011 in a report entitled *Hidden in plain sight*, said that this harassment takes different forms, including bullying, cyber-bullying, physical violence, sexual harassment and assault, domestic violence, financial exploitation and institutional abuse. Harassment is, however, often not reported. This may be because: people with disabilities do not know who to report it to; they fear the consequences of reporting; or they are concerned that police or other authorities will not believe their account.

The inquiry highlights the need for additional data to be collected on the issue, as well as making a number of recommendations for how public authorities could improve their performance in preventing and dealing with disability-related harassment. A 'manifesto for change', outlining the commitments public authorities have made and the outcomes they aim to achieve, is scheduled for publication.

*For more information, see: Equality and Human Rights Commission (2011) Hidden in plain sight: inquiry into disability-related harassment, Manchester, Equality and Human Rights Commission, available at: [www.equalityhumanrights.com/uploaded\\_files/disabilityfi/ehrc\\_hidden\\_in\\_plain\\_sight\\_3.pdf](http://www.equalityhumanrights.com/uploaded_files/disabilityfi/ehrc_hidden_in_plain_sight_3.pdf)*

## Difficulties in accessing justice

Overall, the number of respondents who had formally complained against unfair treatment was in general low among those with intellectual disabilities. In the United Kingdom, though, most of the respondents had made official complaints about their treatment in a wide range of situations.

Most respondents said that the reason they refrained from complaining was the fear of retribution and most of those who had lived in institutions and had experienced unfair treatment never brought formal complaints:

*"Well, to complain is to [...]. It just means things will be worse for me."*

*(Woman, 31, Latvia)*

*"I would be too afraid."*

*(Woman, 32, Romania)*





*"I know lots [of places to lodge a complaint] [...] but I'm always scared they'll find out and then not stand by me."*

(Germany)

*"The manager of the guy who was running the residential home came and gave me a talk and told me that complaints were a threat, and they warned me not to do that again."*

(Man, 54, United Kingdom)

Some of the respondents also feared that they would not be taken seriously:

*"What is the use in complaining? He [the director of an institution] would just say it is your own fault!"*

(Woman, 41, Latvia)

Respondents also reported bad experiences when trying to secure help from law enforcement officials and the justice system. A young man from a small town in Latvia went to the police after a dispute with his relatives but felt the police made no effort to help him. When he returned to the police station to sign the necessary documents, an officer made him sign without letting him first read them or his brother, his support person, take part in the conversation. Later, the policeman warned him not to return to the police station. The policeman, the man said: "threatened to take me to the psychiatric hospital."

*"[The policeman said] 'Did you not do it?' 'Did you not break your own window? Or chuck paint and eggs at your window?' You must be joking! And that's how they treat you, because you have a learning difficulty. They have no respect for us. And sometimes some police say: 'You shouldn't be out here. You should still be locked up.'"*

(Man, 63, United Kingdom)

Some respondents said that they had tried to complain but received no response:

*"I went and complained before the national Ombudsman, the Parliament, the President and the Ministry of Labour and Social Policy many times but there was no reply from anywhere. No one cares for the people who live in homes."*

(Man, 32, Bulgaria)

In Latvia, a woman turned to the media to complain about her mistreatment and succeeded in having the director of an institution dismissed:

*"It was hard to get him out of his chair. I had to fight for about a year. I wrote letters all the time. I only got to bed at midnight."*

(Woman, 46, Latvia)

An important barrier to obtaining redress was lack of awareness about complaints procedures combined with

lack of formal support. In Bulgaria, according to one of the stakeholders, a lawyer with the Bulgarian Helsinki Committee, the low number of complaints can be attributed to the lack of self-advocacy organisations that could raise rights awareness. In her view, persons with intellectual disabilities are mainly supported by carers, often family members, who are less willing to assist in lodging a complaint. In Hungary, stakeholders said that there were many developed advocacy groups for persons with intellectual disabilities. The only respondents in Hungary who could name the institutions to turn to for redress in cases of bad or unfair treatment were part of such self-assertiveness groups.

In the United Kingdom, all the respondents who had lodged complaints said that support to do so was essential. The need for support was echoed by a respondent in Sweden, who explained how his parents and self-advocacy group supported him in appealing a ruling on an unsuccessful complaint against his local authority at the District Court. Research respondents in Sweden, some of whom had brought complaints to authorities and the courts, spoke of lack of awareness concerning organisations that can help in seeking redress and of the scarce information on the operation of support services and the welfare system.

## Summary

While there were important differences between the experiences of respondents from different countries in some areas, there were common themes that cut across all countries. Research respondents spoke, for instance, of limited access to regular community life and independent living. Many lived in community settings that still engaged in characteristic institutional practices. Most were educated in segregated schools or programmes and some faced barriers in establishing their own families and gaining access to the regular labour market.

Those respondents who had experienced large-scale institutions at some point in their past were overwhelmingly negative, especially if they had been placed there involuntarily. They complained of lack of choice in their everyday lives, little or no privacy, a prohibition on intimate relationships, a lack of information, staff's humiliating treatment as well as occasional violence and abuse.

Many people with intellectual disabilities who participated in this research found it difficult or impossible to make decisions about large and small aspects of their lives. While in some countries they could benefit from elaborate systems supporting decision making, in others no such support schemes were reported to be in

place. With many fundamental aspects of life, as well as with small issues of daily living, the respondents often had limited or no choices.

Experiences varied widely with regard to access to justice, but many respondents reported victimisation, discrimination, harassment, bullying and abuse which they found difficult to challenge. Access to justice was limited not least because many did not know about their rights, did not know how or with whom to file complaints or feared that complaints would worsen their situation.

Findings from the field research in the nine countries show that there is a wide gap between the lived everyday experiences of people with intellectual disabilities in Europe and the demands of the CRPD. The results show that although the transition towards more independent living has begun, much remains to be done. Respondents described how their lives are still restricted, but also how they are gradually transformed as they achieve more choice and control over their lives.

Deinstitutionalisation is a key element in this process and much has been achieved, although varying degrees of progress mean that the options available to people with intellectual disabilities for living in the community in the countries covered by the research differ considerably. Despite progress, lack of choice and control over where and with whom to live remains a significant problem. Although most EU Member States have officially embarked upon programmes of deinstitutionalisation, the alternative housing and support options for living in the community that are on offer remain limited. Furthermore, many people with intellectual disabilities cannot find adequately paid employment and lack the financial resources that would allow them to live independently in their own home, as many of them desire.

An important component of independent living is the ability to participate in public and political life through voting and through active involvement in peer support and self-advocacy organisations. Respondents spoke of a lack of political awareness and of the inaccessibility of political processes. They highlighted the contribution of self-advocacy organisations in supporting the political involvement of people with intellectual disabilities and their communication with public authorities, as well as in advocating for their voices to be heard in policy and decision making.

Administrative barriers also curtail individuals' scope to make choices about their lives. Complex and changing rules and regulations serve to alter people's eligibility for benefits and limit their freedom to move to a new town or city without losing their support services, while inaccessible information reduces awareness of entitlements and administrative processes. Similarly, the failure of legal systems to adapt to the needs of people with intellectual disabilities means that recourse to justice in cases of maltreatment remains rare. The lack of legal support and fear of not being believed or prompting retribution further restrict access to justice.

Finally, both respondents and stakeholders expressed concern about the impact of austerity measures taken in the current economic climate that may impact on their opportunities to live independently. Participants were also concerned about the effect public spending cuts can have on self-advocacy groups and other civil society-led support measures.



# 2

## Experiences of persons with mental health problems



This chapter explores some of the complexities people with mental health problems experience in connection with living independently and being included in the mainstream community.

There were a total of 115 people with mental health problems interviewed in this study (see Table 2.1). Roughly half of the respondents (58 out of 115) were between 26 and 45 years old and the majority of the interviewees were women (61 v. 54 men). The largest number of interviewees came from Romania (21), followed by France (16) and Greece (15). The smallest number came from Hungary (eight) and Sweden (nine). More details regarding the sample composition at the national level can be found in Annex 1 of this report.

Almost all of the research respondents had been diagnosed with mental health problems when they were

teenagers or young adults. Although the research focused on their current experiences as adults, some respondents also reflected on earlier experiences when relevant.

### 2.1. Living arrangements

At the time of the interviews all research respondents lived either alone, with a spouse or partner, with parents or other relatives or they lived in group homes. None of the respondents were homeless at the time of the interviews, but Hungarian and French respondents reported having lived on the streets in the past. Some respondents had in the past also lived for longer or shorter periods in psychiatric hospitals and some expected to return there.

Table 2.1: Respondents with mental health problems, by country, age and gender

Country	No. of interviewees	Men					Women				
		Age < 25	26-45	46-65	>66	Total	Age < 25	26-45	46-65	>66	Total
BG	10	0	3	2	0	5	0	2	3	0	5
DE	12	0	2	4	2	8	0	2	2	0	4
EL	15	0	4	4	0	8	0	5	2	0	7
FR	16	0	1	6	0	7	0	6	3	0	9
HU	8	0	1	1	0	2	0	6	0	0	6
LV	12	2	0	2	2	6	1	3	2	0	6
RO	21	0	5	2	0	7	2	11	1	0	14
SE	9	0	5	1	0	6	1	0	2	0	3
UK	12	0	3	1	1	5	0	5	2	0	7
<b>Total</b>	<b>115</b>					<b>54</b>					<b>61</b>

Source: FRA, 2011

Experiences of making choices on where and with whom to live and their living arrangements varied among respondents in different countries. Financial status was a critical factor determining the type of living arrangements, which, in turn, directly affected respondents' scope for decision-making in other areas of their lives.

Some respondents living with their parents or spouses said that their families could be a source of support. Others felt, however, that their own decisions were overridden by their families or they had conflicts with them, and some even felt that their families contributed to their mental health problems. As a result, many respondents expressed a wish for further independence from their families, although economic difficulties prevented them from moving out on their own.

### Living alone, with a spouse or with a partner

In France, Germany, Sweden and the United Kingdom most respondents lived alone or with a spouse or partner. The opportunity to set up one's own home was greatly valued and was directly associated with increased freedom. In the words of one woman:

*"It is a totally different thing when I have my own space, my own home."*

(Woman, 25, Latvia)

Many respondents had come to own an apartment as a result of inheritance or parental support and feared that losing it could mean returning to an institution:

*"It is good for me that I have the house. If they took the house away, I would go to the social care institution, because I do not have anything else. I am so used to it, I feel good at home. I have things to do, I have my own garden. [...] So I think that people need a place of their own if they are able in any way to take care of it, they need their own home rather than a place in the institution."*

(Woman, 53, Latvia)

### Promising practice

#### Supporting housing searches

The urban community of Lille, France, published a guide to inform all authorities involved in housing programmes about aspects to consider in relation to the accommodation of persons with mental health problems. The guide presents information on the different types of housing in the area, on how to find financial support and on access to care and mental health services.

*For more information, see: Lille Métropole Communauté Urbaine (2010) Guide Habitat - santé mentale - Lille Métropole. Logement, hébergement et accompagnement des personnes en difficulté psychique, Lille Métropole Communauté Urbaine, Agence Régionale de l'Hospitalisation Nord-Pas de Calais*

### Living with parents or relatives

The proportion of respondents who lived with their parents or siblings varied significantly. In Sweden and the United Kingdom, for instance, none of them did, while in Bulgaria, Greece, Hungary, Latvia and Romania more than half of the respondents continued to live with their parents or other family members well into adulthood. In many cases, family members provided invaluable support for daily life both in terms of facilitating access to goods, services and leisure activities, and in providing emotional support. Some respondents were happy living with their families:

*"It is my choice to live with my parents. I don't feel [...] overwhelmed by them. I don't feel ready to live on my own."*

(Woman, 31, Greece)

Living with family members was not always a matter of choice. Hungarian respondents emphasised that living with parents or with family members was the only option available to them, even if relationships were strained, in the absence of any viable alternative apart from a social care home. Some respondents described difficult relationships with family members, with relatives sometimes showing prejudice and a lack of understanding:



*“When I lived together with my family, I always had arguments with my mother, because my way of thinking is totally different and she never accepted my point of view. My brother used to call me a sicko, an idiot [...] – he thinks I am completely ill. [...] When I did something at home which someone else did not like they would say ‘take your medication’ – that kind of attitude [...] all the time.”*

(Woman, 25, Latvia)

Although many respondents saw family support as critically important, some, particularly in Bulgaria, Greece, Hungary and Latvia expressed a wish for further independence from their families. But the limited number of places in group homes or other service accommodation, difficulties in securing support with independent living and/or lack of financial resources prevented them from living on their own.

## Living in group homes

The term ‘group home’ refers to a variety of living arrangements usually in an apartment or other small-scale housing. They clearly differ from ‘social care homes’ in that they are smaller in scale and generally more oriented towards enabling residents to have more choice and control over daily living. Typically, resident support services are available and people needing similar types of support tend to be grouped together to live in these establishments. The respondents referred to such settings in different ways, for instance in Bulgaria as ‘protected homes’, in Sweden as ‘serviced apartments’, in Latvia as ‘group apartments’, in Hungary as ‘residential homes’ or in Greece as ‘protected apartments’. At the time of this research several respondents lived in such accommodation in Greece, and, fewer, in Hungary, Latvia and the United Kingdom. Others had prior experience of living in group homes but had subsequently moved into other accommodation.

Group homes triggered mixed reactions. Some respondents considered them as an opportunity to break away from situations of greater dependency either in institutions or with their families. However, a number of respondents argued that they do not offer enough choice and control. Some stakeholders were also critical of the conditions required by group homes. In Sweden, for instance, representatives of user organisations said that in some cases residence at the group home was conditional on taking prescribed medications.

Those respondents who spoke in positive terms about their life in group homes regarded themselves as fortunate to have been given the opportunity to live there:

*“Come and see my room. I like it here. I have everything – here is my bed, my bear, my clothes, my cosmetics. Here is our day room, we have TV sets and we can listen to music on this tape recorder.”*

(Woman, 34, Bulgaria)

One respondent who had moved there with her husband from a social care home characterised the difference between the social care home and the group home as:

*“Night and day.”*

(Woman, 47, Latvia)

A 30-year-old Hungarian woman who had previously lived with her parents appreciated the independence she gained. Others were also satisfied:

*“It was good that I could live there, that they cooked for me and did my room for me. My mother gave me money, I had a car and I could do what I wanted.”*

(Man, 52, Germany)

Many respondents commented, however, on the limited availability of supported living arrangements, such as group homes or half-way houses, a transitional form of residential facility. Stakeholders in Sweden argued that persons with mental health problems tended to have to wait longer than others, for instance than persons with intellectual disabilities, for this type of accommodation and that they were more likely to be placed in outlying areas distant from city centres. The Greek stakeholders stressed that community-based accommodation options are only available to people who had been treated in psychiatric hospitals.

*“A lot of people were in line. They considered your age, and I would never have gotten out if X and I had not married before that.”*

(Woman, 47, Latvia)

## Experiences in psychiatric hospitals and institutions<sup>88</sup>

Deinstitutionalisation programmes are under implementation across the EU with varying degrees of success. In France, Greece, Latvia, Romania and the United Kingdom more than half of the research respondents with mental health problems had lived or had been treated in an institution, mostly psychiatric hospitals, but also, in Germany and Latvia, in social care homes. Respondents had also experienced involuntary hospital

<sup>88</sup> Many of the respondents identified diverse forms of residential facilities – including boarding schools, orphanages, small and large community living facilities, and various other forms of residential facilities – as institutions and described how many of these places had institutional characteristics and practices regardless of the size or number of people living there.

placement, which in most cases they experienced as frightening and unhelpful.<sup>89</sup> Admission and stay in residential hospital care were experienced more positively when respondents had choice and control over the procedure.

A number of respondents noted improvements in the infrastructure and sometimes also in the regimes within institutions in recent years.<sup>90</sup> A 50-year-old woman with recent experience of a psychiatric clinic in Germany said: "I liked it in the ward I went to." Some respondents also highlighted good and productive relations with staff. In Latvia, for instance, hospital staff actively assisted one of the respondents to recover his legal capacity by contacting an advocacy organisation and an attorney. Once he had regained his legal capacity, the man was able to choose to leave the hospital and move into a group apartment. Good interaction with staff underlies the positive experience of a four-month stay in hospital described by a British woman:

*"There wasn't anything scary. Everybody seemed really nice. People were always having conversations with you or other people in the same predicament. And there were visitors coming in and everybody seemed really friendly."*

(Woman, 43, United Kingdom)

Other respondents, however, opposed living in an institution:

*"The first floor is a joy. There are birds, there is a conservatory. It is nice to relax there. But I still do not want to go there. I want to avoid that place. I want to forget everything that happened."*

(Woman, 40, Latvia)

*"Residential homes, the way the people live in homes, scary, oppressive and sometimes even, it makes me angry, it makes me want to scream, the conditions there and that would be the last way I'd want to live."*

(Woman, 52, Germany)

Furthermore, respondents argued that improvements have not occurred across the board and there is still considerable variation between and even within establishments:

*"So you can go in one ward in one place and it's actually fairly pleasant, everything's clean, people are in distress but it's managed and they've got their own space, and there's privacy and dignity. [...] and then you'll go on another ward in another place and it is bedlam. You don't get a sense that anybody is in control there; that anybody's being helped; there are people in distress who are not being catered for and actually a very unsafe environment. You can go in the same hospital site and go in two different wards and it can be completely different and yet they're physically mirror-wise the same."*

(Woman, 46, United Kingdom)

## 2.2. Daily living

The experiences of participants across the nine EU Member States revealed problems in accessing general services and specialised community services either due to discrimination or due to the lack of good networks of financially accessible services. While most respondents had received mainstream education, disruption to their studies and a lack of reasonable accommodation were mentioned. Employment was of the utmost importance to all respondents, but many felt discriminated against and trapped in a system of welfare benefits that was not conducive to active participation in the open labour market. Lack of employment and dependence on welfare benefits or family income made for a precarious financial situation that, in turn, prevented them from participating in community life.

### Education

Most respondents had experienced general mainstream education and finished secondary school. While in some cases they held university degrees, they reported having their first symptoms of mental health problems in their teenage years, coinciding in some cases with their university education.

Two experiences related to education were commonly reported by respondents: first, bullying by either classmates or teachers in school and second, disruption of secondary and university education due to episodes of mental health problems. Secondary school was described as a difficult period by respondents in Greece, Latvia, Romania, Sweden and the United Kingdom, where half of the respondents said they had been bullied. Several respondents described how they felt unable to protect themselves or to ask for help from their teachers or parents:

*"I heard them speaking about me as a crazy person but I was proud somehow and shy at the same time and did not say anything to my parents."*

(Man, 43, Bulgaria)

<sup>89</sup> The issue of involuntary placement and involuntary treatment is discussed in FRA (2012).

<sup>90</sup> The timeframes mentioned varied, e.g., 20 years was mentioned in the United Kingdom, whereas in Latvia respondents said that improvements started in 2000.





*"I had my first anxiety attack when I was 17. I was extremely inhibited and I could not talk to teachers and classmates. Finally, I went to the headmaster's office, banged my school books on his desk and said, 'I quit!'"*

(Woman, 46, Sweden)

Respondents in Bulgaria and Romania faced particular difficulties in continuing education after their first crisis and treatment either because of the demands of treatment or because the school failed to accommodate their needs. In Romania, two-thirds of the respondents had completed secondary education and/or had done two or three years of university, but only one had a university degree.

*"They applied electroconvulsive shocks to me. I could not continue high school. My relatives moved me to an evening form of education. But I was very frequently in hospital and did not like the school very much."*

(Woman, 48, Bulgaria)

*"My mother and my stepfather moved me to another high school in S. after the first crisis. I had to take exams, like entry exams, to be enrolled in it. Later on I had lower marks at school but still enough to be admitted to university."*

(Woman, 29, Bulgaria)

*"If I'd got my diagnoses earlier, staff in school would have known better about my disability and it would have been easier for me to adjust. [...] School staff did not understand or attend to my needs."*

(Man, 31, Sweden)

As with earlier schooling, one particular challenge was the failure of authorities to account for the fluctuating nature of mental ill health. One woman in the United Kingdom complained about being required to pay for one academic year again although she had missed a considerable amount of the previous one due to mental health problems. In Latvia, a woman reported a lack of available adjustments:

*"I am disabled but [...] in reality they do not pry into your private life. [...] We are given assignments, you do them and whatever you do in your free time is your own business, regardless of your disability or social status. For a while I received a stipend that's paid to disabled people or poor people or those with children. [...] The rules are the same for everyone, and I may not be able to study as diligently as someone without a disability, perhaps. All the students have to meet the requirements of the study programme, and the lecturer is not going to give you an easier time just because you have a disability."*

(Woman, 25, Latvia)

## Employment

As mentioned earlier the Equality Employment Directive<sup>91</sup> prohibits direct and indirect discrimination, as well as harassment and any instruction to discriminate on grounds of disability, religion and belief, age and sexual orientation. It covers the fields of employment and occupation, vocational training and membership in employer and employee organisations. Article 5 of the directive asks employers to take appropriate measures to enable persons with disabilities to access, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on employers ('reasonable accommodation'). The 2010 FRA report *The legal protection of persons with mental health problems under non-discrimination law*<sup>92</sup> provides a comparative legal analysis of the current situation showing that in almost all EU Member States non-discrimination legislation protects persons with mental health problems, who also benefit in most cases from reasonable accommodation measures in employment.

EU Member States have implemented a range of initiatives to improve the employment rates of persons with mental health problems. In Sweden, for instance, labour market policies have specifically targeted people with mental health problems as one of the most disadvantaged in the labour market. Targeted initiatives to raise employment levels include work internships, subsidised positions, sheltered employment in the public sector, and special introductory and educational support, including the provision of a support person through the Special Introductory and Educational Support Measures (*Särskilt introduktions och utbildningsstöd*, SIUS). In 2009, 23 % of the new users of this programme were persons with mental health problems. Several Member States have also introduced mandatory quotas for the employment of a minimum share of people with mental health problems in the private and public sector.<sup>93</sup>

Respondents in most countries had experience working in the open labour market although at the time of the research half were not employed and few were in paid employment. Respondents reported that they found working with other people and assisting people fulfilling. Most respondents agreed, however, that there are three key barriers to employment: discrimination; lack of reasonable accommodations or job adjustments; and lack of social support services to help them find and retain work. Given these difficulties, compounded by the

91 Council Directive 2000/78/EC, OJ 2000 L 303.

92 FRA (2010).

93 See: [www.nda.ie/cntmgmtnew.nsf/0/84AA79B029E870AE8025729D0046CAED/\\$File/people\\_with\\_disabilities\\_in\\_public\\_sector\\_04.htm](http://www.nda.ie/cntmgmtnew.nsf/0/84AA79B029E870AE8025729D0046CAED/$File/people_with_disabilities_in_public_sector_04.htm).

economic crisis, most respondents were unemployed or had found only unstable and short-term employment.

Most respondents employed in the open labour market were in Germany and Latvia, where a third of respondents had jobs at the time of the interviews, and in Hungary, where three out of eight respondents were employed. In France, two-thirds had worked on the open labour market at some time during their working lives. In contrast, just one Romanian respondent reported such employment. Most of those who were employed, however, felt that their job did not provide them with a sufficient income. The proportion of respondents in supported employment varied considerably. For instance, in Bulgaria, respondents worked part-time in community day centres, while in Germany and Sweden some respondents were in supported employment. In Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom more than half of respondents said that they were unemployed. In the United Kingdom, more than half of respondents had tried to mitigate the lack of employment opportunities by working voluntarily, mostly in jobs connected to mental health.

Several respondents felt that lack of education contributed to their employment problems:

*“What I am detecting is a degree of intellectual frustration because [mental health service users] have lost their chances of a good education and therefore a good, satisfying sort of workplace environment. And a lot of that comes from the fact that if you fall out of education at some point, always in the past you were treated with some disdain. You didn’t fall out because of emotional problems, but because you’re not good enough. Whereas I’m finding it’s just not true, I can see the evidence of that now.”*

*(Woman, 55, United Kingdom)*

Others complained of difficulties in obtaining and retaining work because of discrimination:

*“The public job advertisements at the Employment Agency Department contain the following information: ‘people assessed by medical commissions as people with reduced working capacity are allowed to apply’ and below this there is a statement that these people must not have a mental health problem.”*

*(Woman, 51, Bulgaria)*

*“I went to apply for a job in a restaurant. They saw me with my stick and asked me whether I broke my leg. I explained to them about my muscle problem. [...] They told me to bring my medical assessment document to prove I [had] a disability. But when they saw in it that my main disability [was] a mental health problem, they said that they [were] sorry but would not hire me.”*

*(Man, 47, Bulgaria)*

Respondents in Hungary spoke of problems with employers who refused to hire people taking medication for mental health problems – especially when the work involved contact with children or machinery.

*“I started to work in an elementary school as a cleaner. After two weeks I had to go to a medical check-up. The next day I went to work as usual and the boss wanted to see me. At first I thought there was a problem with my work, but he said that I did my job well, there were no complaints, but he still had to discharge me. I asked him why. I started to cry, which I felt awful about. He said that I was not allowed to work closely with kids while I was taking such strong medications. I have had the same problem in many other work places.”*

*(Woman, 27, Hungary)*

To avoid discrimination and minimise the risk of unfair treatment, many respondents opt not to disclose their disability. A woman in Hungary, who had a job with a secure salary, attributes her success at work to the fact that she has not told anyone about her mental health problems:

*“I really, really keep it as a secret, as a huge secret.”*

*(Woman, 33, Hungary)*

Other respondents highlighted the potential risks involved in revealing a mental health problem:

*“As soon as I disclosed [my mental health problem] my probationary period got doubled [...] and I got quite a lot of personal victimisation. [...] If I didn’t reply to an email straight away they’d be on the phone saying: ‘Why haven’t you – you need to be able to answer us at any point’. [...] In the end [...] I resigned.”*

*(Woman, 38, United Kingdom)*

*“I was working at a supermarket warehouse. I did not tell them I had a problem. They wouldn’t have recruited me if they had known. I panicked twice and had to be absent. My sister tried to make an excuse for me. However, after the second time I did not go back. What could I say? That I had a problem? They would ask me why I had not informed them in the first place. What could I say?”*

*(Man, 40, Greece)*

If they do not report their needs, persons with disabilities cannot benefit from their entitlement to reasonable accommodation. Many respondents pointed to the need for adjustments on the parts of employers, in particular regarding flexible working hours or altered work tasks but said that in reality it was difficult to obtain them:

*“I need half a shift, but unfortunately no one will give you one. It is impossible. If you want a half shift, then ‘get lost’. And if you don’t get lost, they offer you less official work and you get less money.”*

*(Woman, 40, Latvia)*



*"I'd like to go to work at some point. But I'm so scared of working full time [...] I've had to take time off work to get 1.5 years' therapy and that took me ages to fight for. If I was at work, I couldn't take time off, people say you have flexible hours but realistically, all these things don't work with [...] time off to see a doctor."*

(Woman, 32, United Kingdom)

Given the difficulty of obtaining work on the open labour market, some respondents worked in 'sheltered' or 'protected' employment schemes. While the exact nature of sheltered workshops varies, the WHO describes sheltered employment as "[...] employment in separate facilities, either in sheltered businesses or in a segregated part of a regular enterprise [...] intended for those who are perceived as unable to compete in the open labour market."<sup>94</sup> Such schemes may offer a useful mechanism for developing work-based skills and confidence and introducing people into the labour market, but there is a risk that they operate away from mainstream society. Furthermore, being associated with a sheltered workshop can itself be a source of disadvantage when attempting to find work on the open labour market:

*"I said I'm at a workshop at the moment and I just wanted an internship to start with, but I noticed that that was it, and they just told me to come back later."*

(Woman, 44, Germany).

For many respondents voluntary unpaid jobs fulfilled the need for interaction with people and gave them a sense of purpose and of having contributed something of value to society:

*"[...] those grey, flat weekdays, all the same, monotonous, that monotony, I do not know [...] but it is pretty bad, so I would like to go to work somewhere to switch off, to be among people, because my illness is much worse if one is at home."*

(Woman, 36, Hungary)

*"You can give as well as take and bring some joy to someone else. [...] To live like you are useful to somebody else and yourself, to have meaning in life and understand what life is all about. To merely live like you just exist is not what living is about. To only think about eating and sleeping [...] and taking care of your other bodily functions. That's not a life."*

(Woman, 47, Latvia)

*"Voluntary work is a good option for people recovering from mental ill health and participation in paid employment is low because the system for getting back into work is very inflexible. [...] However voluntary work, which has the role of rehabilitation now that most of those services have gone, is being affected by local authority spending cuts – many work in voluntary organisations which are being closed."*

(Stakeholder, United Kingdom)

## Promising practice

### Finding employment and being employed

Legislation in **Greece** allows people with mental health problems to set up limited liability social cooperatives, or 'KoiSPE', with a membership of up to: 35 % of people with mental health problems; 45 % of mental health professionals; and up to 20 % of other individuals and sponsoring organisations. The cooperatives have independent legal and tax status, are exempt from corporate taxes excluding value-added tax (VAT) and can carry out any economic activity. As of March 2011, 16 KoiSPE were in operation, employing more than 200 people of whom 45 % were people with mental health problems living in the community.

Labour market programmes to assist persons with intellectual disabilities or mental health problems in **Sweden** include Special Introductory and Educational Support Measures (*Särskilt introduktions och utbildningsstöd*, SIUS). In 2009, 22 % and 23 % of new participants in the programme were persons with intellectual disabilities or with mental health problems, respectively.

*For more information on KoiSPE, see: European Commission, Legal frameworks: A first step towards social and economic integration of the mentally ill. The EU social protection social inclusion process. Good practice article, available at: <http://ec.europa.eu/social/BlobServlet?docId=733&langId=en>; and on the labour market programme in Sweden: Public Employment Service (Arbetsförmedlingen) (2010) Arbetsmarknadspolitiska program. Årsrapport 2009. Ure 2010:1, p. 122*

## General healthcare

For most respondents living in the community the most important healthcare relationship was with their local general practitioners (GPs) who provided general healthcare but could also act as access points for additional services related to their mental health. The respondents' experiences varied significantly in terms of how they were treated by their GPs and the types of services that they were able to access through them. In the United Kingdom, for instance, the success of interaction with the GP was seen as directly related to whether or not the GP had had special training on mental health issues:

94 WHO (2011), p. 242.

*“At the moment I have an excellent GP who is psychotherapy-GP trained so he’s a real diamond.”*

(Woman, 55, United Kingdom)

A recurrent theme in the interviews was the GPs’ attitudes to persons with mental health problems:

*“They (the medical profession) must not be afraid of persons with mental health problems, we are not dangerous.”*

(Man, 42, Sweden)

Respondents commonly experienced ‘diagnostic overshadowing’<sup>95</sup> when healthcare staff attributed physical illnesses or problems to their mental health problems and consequently did not take them seriously:

*“As soon as my blood pressure rises, there must be something wrong with my psyche, even if I have had bronchitis. [The GP] looks for indications, after all.”*

(Woman, Latvia)

*“My family doctor did not take me seriously when I talked about my physical complaints.”*

(Man, 42, Sweden)

Respondents in Hungary and Latvia, for instance, complained that when general health services identified someone as having a mental health problem they were often referred to a psychiatric hospital without providing the services they originally sought:

*“It really is like there is a mark on you. No matter whether you have a headache or your blood pressure is up, the solution is to take you to Tvaika Street [Riga Psychiatric hospital]! End of story. The doctor thinks you have a temperature because you imagined it yourself, so your heart starts beating faster and you get hotter.”*

(Woman, Latvia)

Respondents complained, for instance in Hungary, that psychiatric hospitals did not pay attention to physical ailments either:

*“I mentioned a couple of times during the ward rounds that my leg was sore, because I could not even stand. They took my medication that I had brought to the hospital, e.g. medication for heart disease, diuretics. They had not given me these pills for a week; of course I had pain in my leg. When I told the doctor during the ward round that I could not do anything and was in pain, that I missed the diuretic, the doctor told me that this was a psychiatric unit and not a hospital for internal diseases.”*

(Woman, 27, Hungary)

Respondents in Romania said that when they had a general health problem they were either referred to another specialist or they were prescribed medication which had been given to them while in a psychiatric hospital, where they had access only to psychiatric drugs.

Another issue identified by respondents was the lack of thorough information about their diagnosis, medication and potential side effects. Some respondents argued that they had not received thorough information from either mental health specialists or GPs. They mentioned instances where medication was prescribed without any explanation of how to take it or where little information was provided about the progress of their treatment and little opportunity given for follow-up consultations.

In Greece, respondents reported positive experiences in regard to the general healthcare they received while in institutions. They referred to healthcare services as an integral part of the treatment they received with regular general check-ups and access to dental and ophthalmological services. Nevertheless, they also said that they would like to be better informed about their medication and its effects before being treated.

## Community-based health services

A variety of community-based health services had been accessed in some form or other by most respondents. In Bulgaria all respondents said that they needed more such community services, while in Hungary, Sweden and the United Kingdom a lack of access to these services was mentioned. In Latvia, the respondents said the only specialised community-based care service for people with mental health problems is outpatient visits to psychiatrists. Generally respondents reported a preference for ‘talking therapies’<sup>96</sup>

*“A psychotherapist. That is essential. That is the main thing, so I can get all my worries off my chest, because some little thing can knock me over, some feeling or thought.”*

(Woman, 40, Latvia)

According to respondents access to this type of psychotherapy was often not easy, as they were not always available as part of the health system. In Latvia and Romania, for instance, access to such therapies was made available, on a limited basis, through NGOs. In the United Kingdom some respondents said that certain community-based services offered alternative therapies to medication, such as relaxation and anxiety management.

<sup>95</sup> More information on ‘diagnostic overshadowing’ in Thornicroft, G., Rose, D., Kassam, A. (2007) ‘Discrimination in health care against people with mental illness’, *International Review of Psychiatry*, 19(2):113-22, available at: [www.ncbi.nlm.nih.gov/pubmed/17464789](http://www.ncbi.nlm.nih.gov/pubmed/17464789).

<sup>96</sup> For more information, see [www.nhs.uk/Conditions/Counselling/Pages/Talking-therapies.aspx](http://www.nhs.uk/Conditions/Counselling/Pages/Talking-therapies.aspx).





In Germany, according to the Social Code (Article 37a SGB V), people with mental health problems are entitled to receive personal assistance in their use of medical treatment and services. This service is known as sociotherapy (*Soziotherapie*) and is available for a period of three years. This entitlement has been in existence for 10 years. Many practical and administrative problems involved in its implementation, however, have resulted in low take-up and lack of use, with only a minority of people with mental health problems having used it. An evaluation carried out in 2005 showed that only 2 % of the budget for this service had been used.<sup>97</sup>

Strict eligibility criteria can also restrict access to the services offered by day centres or community mental health teams or clinics. In the United Kingdom, for instance, a respondent argued that the fluctuating nature of his mental health problem generated eligibility difficulties:

*“So then I lost my CPN [community practice nurse]. And then when I actually became unwell, and needed one, I had to go through the whole system again. So I had to go to the doctor’s, then make an appointment to see a CPN and then get shoehorned back into the system”*

(Man, 44, United Kingdom)

British respondents appreciated the support provided by community-based services and were concerned about the impact of public spending cuts on the local centres they relied on:

*“They don’t want to spend money on prevention [...] even though a wellbeing centre might cost less. They want to get rid of local wellbeing services and they don’t understand why we need them. They are the things that get us through.”*

(Woman, 32, United Kingdom)

There was recognition particularly among stakeholders of the important role played by these centres and the services they offered and of the importance of developing flexible approaches which catered for the needs of people at evenings and weekends as well as during normal working hours. In the words of the director of a day centre in Bulgaria, echoed by Greek stakeholders:

*“We do not integrate our clients into the society as the design of [...] services such as the day-care centre requires that the client comes into our building in the morning and goes home in the evening. We need flexible services which would allow [us to meet] the individual needs of the clients.”*

(Stakeholder, Bulgaria)

In this light, stakeholders in Bulgaria and in Latvia expressed concern about recent large investments on the renovation of psychiatric hospitals but not on developing community-based support services and structures. The European Commission’s proposal for pre-conditions for receiving EU structural funds for the period 2014 to 2020 reflects the preferences expressed, stating as one of the conditions for receiving funds that a national strategy for poverty reduction must be in place that “includes measures for the shift from residential to community based care” and “includes clearly measures to prevent and combat segregation in all fields”.<sup>98</sup>

97 Germany, Aktion Psychisch Kranke (HG.) (2005) *Evaluation der Umsetzung des § 37 a SGB V (Soziotherapie)*, available at: [www.apk-ev.de/Datenbank/projekte/0022\\_Bericht\\_Soziotherapie\\_09\\_01\\_06%20kompl.pdf](http://www.apk-ev.de/Datenbank/projekte/0022_Bericht_Soziotherapie_09_01_06%20kompl.pdf).

98 European Commission (2011), p. 148.

### Promising practice

#### Bringing mental health services into the community

The NGO *Chovekolyubie* ('Philanthropism') in Pazardzhik, **Bulgaria**, has developed services through its Centre for Mental Health, including psycho-social rehabilitation programmes, a crisis intervention service and a social enterprise. The business includes a studio to manufacture souvenirs, a shop for honey and natural bee products, a refreshment stand and a vegetable garden. Users of mental health services work at the Centre: five to 11 people with severe mental health problems are on the *Chovekolyubie* staff at any given time.

In **Romania**, the Orizonturi Charity Foundation in partnership with the Psychiatric Hospital of Câmpulung Moldovenesc and local town halls has implemented a project to provide community alternatives to psychiatric assistance. The project aims to pilot mobile healthcare and social intervention in the small towns and rural communities covered by the psychiatric district. Activities are focused on developing alternative and integrated services at the Câmpulung Moldovenesc Mental Health Centre by involving the local community and service users in their design and implementation.

For more information on *Chovekolyubie* in Bulgaria, see: [http://chovekolubie.org/?page\\_id=80](http://chovekolubie.org/?page_id=80); and on Orizonturi in Romania: [www.echipamobila.ro](http://www.echipamobila.ro)

*"We learned from scratch [...] how to cook, because I spent so many years in the institution, 14 and a half in total, and I did not cook anything. Personal hygiene - we learned all about that [...], then we went to the laundry room to learn how to iron. [...] Then there were psychology lessons, [...] then we learned about laws, our rights and duties."*

(Woman, 47, Latvia)

Most respondents wanted to live independently whether in a group apartment or in their own home. However, some did not feel ready to make the move to independent life. In particular, respondents in Greece did not always feel confident enough or ready to reduce their dependence on family members. Similarly, in Bulgaria older respondents were unwilling to separate from their families fearing poverty or that they would not be able to cope with everyday activities and payments. While independent living skills are important, other practical issues are also important for achieving a successful independent life. According to some stakeholders a major issue is the availability of housing and support services, which can be a serious obstacle to moving out of psychiatric hospitals and into community settings. In Latvia, for instance, a representative of Mental Health Care Nurses, which is also responsible for a social care centre, said that around a third of those residing in her centre could live at home if they were provided with housing and community support services. A representative of the Latvian Ombudsman's Office expressed a similar view, suggesting that a recent visit to a psychiatric hospital indicated that about a third of the patients could live in the community if they had alternative community-based care, including personal assistants.

## 2.3. Support for daily living

Persons with mental health problems may require support to improve choice and control over their daily life. Respondents spoke of their experiences with various forms of such support ranging from assistance in developing independent living skills; formal support options; informal support from family and friends; and support provided by NGOs and user groups.

### Development of independent living skills

Developing skills for independent living is essential for a successful transition from institutional to community living. Such skills may refer to essential daily activities such as getting dressed, washing or cooking to paying the bills and dealing with administrative tasks. In Latvia, a woman described her training experience in independent living skills after a lengthy period of living in a social care home:

### Formal support options

The provision and availability of support services differs reflecting a variety of welfare regimes as well as the extent of progress towards deinstitutionalisation and community living. In Sweden, for instance, emphasis has been placed on the importance of allowing people with mental health problems themselves to choose who assists them. Stakeholders, however, noted that people with mental health problems can have difficulties accessing these services, as they are restricted to those persons with disabilities who have "severe and persistent difficulties in managing daily life". In France, people with mental health problems living independently can benefit from the support provided by the Support Service for Social Life (*Services d'accompagnement à la vie sociale*, SAVS)<sup>99</sup> and the Medical-social Support Service for Disabled Adults (*Services d'accompagnement*

<sup>99</sup> France, Décret n° 2005-223 du 11 mars 2005 relatif aux conditions d'organisation et de fonctionnement des services d'accompagnement à la vie sociale et des services d'accompagnement médico-social pour adultes handicapés.





*médico-social pour adultes handicapés, SAMSAH*).<sup>100</sup> SAVS provides independent living support for adults with mental health problems, including housecleaning, shopping and cooking, as well as administrative tasks. SAMSAH supplements the support of SAVS by coordinating people's medical care.

A number of other EU Member States have introduced legal reforms to provide personal assistance but have faced major challenges meeting demand for support services and in implementing the policies. In Bulgaria, for instance, the Regulations for Implementation of the Social Assistance Act adopted on 1 June 2010 provide for personal assistance, but it is limited to 10 hours per year. Eligibility for assistance is linked to the level of reduced labour capacity or to the financial income of the users. The new Disability Law in Latvia, which entered into force on 1 January 2011, introduces the right to have a personal assistant initially for persons with visual impairments and from 2013 for persons with other disabilities, up to a maximum of 40 hours per week.

Several EU Member States have implemented innovative provisions to promote the choice and control that persons with mental health problems have over the formal support services they use. Alongside personal assistance, one notable development has been the concept of personal budgets, for example in Germany, where persons with mental health problems make up the largest group of recipients: an evaluation carried out as part of the federal Personal Budget Pilot Project (2004–2007) found that 41% of budget recipients were categorised as persons with mental health problems.<sup>101</sup> In the United Kingdom, the English government, as part of the move towards more personalised services, issued guidance to move towards more extensive use of direct payments, in particular by those groups that have not made wide use of them up to now, including people with mental health problems. According to this guidance local councils have not just a power, but a duty, to offer direct payments in most circumstances.<sup>102</sup> Furthermore, since 2009, people judged to lack mental capacity in England have been able to receive direct payments,

opening up the possibility for a third party to directly receive and manage the payment. Recipients of direct payments may decide who to employ, the hours they work and the tasks they carry out.

Respondents across each of the nine countries accessed specialised support services to facilitate independent living; however, the proportion of respondents using such services varied considerably. In France, Germany, Hungary and Sweden fewer than half of those interviewed accessed specialised support services to facilitate independent living, whereas in each of the three Member States Greece, Romania and the United Kingdom all but one respondent did.

Formal support in the form of personal assistance was an exception. Only a small number of respondents in Germany, Sweden and the United Kingdom brought forward experiences of formal support in the form of personal assistants. In Bulgaria and Greece, none of the respondents had any experience of personal assistant services. In Latvia, respondents claimed that support services, including personal assistants, are currently unavailable.

Unsurprisingly, respondents from different countries identified some similar issues which affected their ability to carry out day-to-day activities and with which some of them felt they required assistance. In Sweden, for instance, respondents stressed that it was important to ensure that support systems are sufficiently flexible to provide the appropriate solution for each individual and that their availability should not be tied to particular forms of accommodation, such as group homes. In the United Kingdom, respondents who did not use the direct payment system felt they had little control over who assisted them and the service they were given. While one respondent was campaigning for the wider use of direct payments by people with mental health problems, others expressed concern about the potential stress associated with employing staff and the risk that local authorities might replace other services with direct payment.

Respondents had experienced a range of state-funded formal 'advocacy support'. Mental health advocacy according to the WHO<sup>103</sup> was developed to promote the human rights of persons with mental disorders and to reduce stigmatisation and discrimination. It consists of various actions aimed at bringing down the major structural and attitudinal barriers to achieving positive mental health outcomes in populations and is considered to be one of the eleven areas for action in any mental health policy. According to the Office of the Public Guardian in the United Kingdom, for instance,

<sup>100</sup> France, *Ministère de la santé et de la solidarité. Ministère délégué à la sécurité sociale, aux personnes âgées, aux personnes handicapées et à la famille. Note DGAS SAVS SAMSAH 2006*[1]. Les services d'accompagnement à la vie sociale (SAVS) et les services d'accompagnement médico-social (SAMSAH).

<sup>101</sup> Metzler, H., Meyer, T., Rauscher, C., Schäfers, M. and Wansing, G. (2007): *Begleitung und Auswertung der Erprobung trägerübergreifender Persönlicher Budgets - Wissenschaftliche Begleitforschung der Modellprojekte „Trägerübergreifendes Persönliches Budget“*, available at: [www.bmas.de/portal/23072/property=pdf/f366\\_\\_\\_forschungsbericht.pdf](http://www.bmas.de/portal/23072/property=pdf/f366___forschungsbericht.pdf).

<sup>102</sup> See United Kingdom, Department of Health (2009 – revised 2010) *Guidance on direct payments for community care, services for carers and children's services*, available at: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_104840](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_104840).

<sup>103</sup> For a more general discussion of mental health advocacy, see WHO (2003) *Advocacy for mental health: mental health policy and service guidance package*, Geneva, WHO, available at: [www.who.int/mental\\_health/resources/en/Advocacy.pdf](http://www.who.int/mental_health/resources/en/Advocacy.pdf).

advocacy is taking action to help people express their views and wishes; secure their rights; have their interests represented; access information and services; and explore choices and options.<sup>104</sup>

In the United Kingdom three respondents received the support of an independent mental health advocate<sup>105</sup> shortly after being involuntarily detained in hospital. Several respondents had also served as or were being trained to act as advocates or peer supporters for other people with mental health problems. In Sweden, two respondents spoke very positively about their experience of assistance from personal agents or personal ombudsman (*personligt ombud*):

*“He learnt a lot about me and my needs; he was a person who listened to me and we still keep in touch.”*

*(Man, 30, Sweden)*

The respondent no longer had a personal agent because none were available in his district. Other respondents as well as stakeholders expressed regret that this scheme, which was assessed very positively, was not available more widely.

<sup>104</sup> For example, see United Kingdom, Office of the Public Guardian (OPG 606) *Making decisions: The Independent Mental Capacity Advocate (IMCA) service*, available at: [www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act](http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act).

<sup>105</sup> For more information on the independent mental health advocate (IMHA) in the United Kingdom, see [www.dh.gov.uk/en/Healthcare/Mentalhealth/InformationontheMentalHealthAct/DH\\_091895](http://www.dh.gov.uk/en/Healthcare/Mentalhealth/InformationontheMentalHealthAct/DH_091895).

## Promising practice

### Supporting decision making: the personal agent or ombudsman

In Sweden advocacy support is provided through the institution of the personal agent or personal ombudsman (*personligt ombud*) who support people with mental health problems, enabling them to enjoy a more independent life and equal opportunities in participating in community life. Their role is to work for the relevant person to assist them with benefits, entitlements and administration to secure their accommodation and income.

Personal agents are highly skilled professionals who work on individual assignments independently from government and healthcare providers in many municipalities. They are not part of the guardianship regime and no deprivation of legal capacity is involved. They only act upon the decisions of their ‘clients’. Building up a trusting relationship in which this is possible can be time consuming and therefore the engagement by the personal agent needs to be long-term, usually for several years.

The central government covers part of the personal agent’s salary, with municipalities funding the rest as well as additional costs such as premises and cars. County councils co-fund about 10 %.

Personal agents are available to adults who require support in their daily lives due to mental health problems and, who may also have a substance abuse problem and/or be homeless. Each year, thousands of people are helped by around 300 personal agents, who have an average of 15 or more clients per year. There is no formal referral procedure, which means that getting a personal agent is a fairly straightforward matter. The fact that establishing personal agents is not compulsory for municipalities means, however, that their availability is not guaranteed. As cases are assessed on an individual basis, there may be waiting lists. In some parts of Sweden young people with a psychiatric disability are given priority; in others, priority is given to those with children.

Personal agents focus on their clients’ strengths. The agents help to create opportunities for greater choice and control over their social situation, thus increasing their chances for more independent living. In this sense, personal agents function as tools in a process in which the client develops greater self-reliance.

For more information, see: [www.personligtombud.se](http://www.personligtombud.se) and [www.ypos.se](http://www.ypos.se)

## Support from family and friends

Respondents referred to the significant assistance provided by family and friends in the context of strong relationships based on affection and trust. A number of respondents in Latvia, Sweden and the United Kingdom referred to the assistance in practical matters or decision making provided by spouses or partners. One man explained that he always sought his wife's advice before making a significant decision:

*"My wife's opinion is most important. Then comes myself, perhaps my father, mother or brother, in that order. [...] I always carry my mobile phone, and in any situation in life we [the interviewee and his wife] call each other."*

(Man, 47, Latvia)

In Bulgaria and Greece, respondents stressed the importance of parental and sibling support. One man explained his difficulty in dealing with money and the support his sister gives him with it:

*"I do not pay bills. [...] My sister does this as she studied to be a shop assistant and she is good at this. [...] If they give me the exact amount of money I can do it but when I shop the bill is not right at the end."*

(Man, 41, Bulgaria)

In the United Kingdom, a woman explained how she relied on her friends at a day centre for advice. Another relied on friends and family to let her know when she was beginning to appear unwell so that she could organise medical treatment accordingly.

## Support provided by NGOs and user groups

NGOs and peer-advocacy or user-led groups provide many services that enhance participation and inclusion in community life. In some EU Member States, the involvement of user-led groups in service provision has been specifically promoted and facilitated by the government. Since 2005 France, for instance, funds the participation of people with mental health problems in mutual assistance groups<sup>106</sup> (*Groupes d'entraide mutuelle*, GEM). These services differ from medico-social services in that they are managed by associations governed by people who themselves have mental health problems, providing new opportunities for people with mental health problems to express themselves and to search for their own solutions as service users. In 2010, 340 GEMs received €24 million in state support. An official evaluation<sup>107</sup> in 2008

confirmed that the GEMs brought benefits but noted that not all GEMs are managed by users' organisations.

Respondents who attended a GEM said that it helped them to maintain a good level of social interaction and to expand their social participation. Stakeholders also appreciated the work and impact of self-help groups:

*"Even among organisations governing self-help groups, it seems to be unthinkable to give responsibilities to users – [for example], keys and the ability to spontaneously organise meetings without other people – even though this is specified in the legislation. The GEMs were actually created in order to allow people with mental health problems to gain autonomy, to dare to be something other than just medical cases and sick people."*

(Stakeholder, France)

Peer advocacy groups have also been instrumental in assisting persons with mental health problems to select support options and in encouraging them to become involved in monitoring government-provided support. In Sweden, for instance, managing personal assistants can be an arduous task for a user, particularly as they often have several assistants to manage. User organisations, such as Equality, Assistance and Community (*Jämlikhet, Assistans och Gemenskap*, JAG) provide educational activities to support them in dealing with such tasks. In addition, user support centres (*Brukarstödscentrum*) provide basic information about rights, how to interpret information and the entitlement criteria of welfare authorities. They also help to formulate applications for services and assist in bringing complaints to the authorities and courts. Furthermore, user audits (*brukarrevision*) have become quite common in mental health care provision. These systematic and independent assessments performed by users of mental health care services serve as an enabling way to ensure service quality.

Respondents who had received support from NGOs and user groups were very positive, but they often raised the issue of funding. Respondents in the United Kingdom, for instance, were concerned about the possible effects of public sector cuts on day care centres:

*"I just think that for the first time in my life, I am getting, I am really being treated as an individual, not as a diagnosis. I have never in my life experienced such support, not even from my own family. And the only bad thing is the threat of losing it of course."*

(Woman, 55, United Kingdom)

Respondents also regarded as important the opportunities to develop other skills, to socialise and meet people as well as the support network such centres generate. One man mentioned the assistance a Latvian day centre provided with paying his bills electronically

<sup>106</sup> More information available at: [www.oisis.fr/](http://www.oisis.fr/).

<sup>107</sup> France, *Instruction DGAS/3B n° 2008-167 du 20 mai 2008 relative aux groupes d'entraide mutuelle pour personnes handicapées psychiques*, available at: [www.sante.gouv.fr/fichiers/bo/2008/08-06/ste\\_20080006\\_0100\\_0087.pdf](http://www.sante.gouv.fr/fichiers/bo/2008/08-06/ste_20080006_0100_0087.pdf).

and the opportunity it offered him to develop his computer skills. In Romania, some respondents who had used psychological counselling services provided by day care centres operated by NGOs stressed the importance of the social interaction the centres provide, as well their help in making relevant information accessible. One respondent said that using the services of an NGO day care centre had cut the length of his hospitalisation stays.

*"[...] put the focus on patients with mental health problems, they include them in this society and do not exclude them as the others do."*

*(Man, 44, Romania)*

In Hungary, a third of the respondents had used day services run by NGOs, which they said offered support to deal with the lack of appropriate social relationships and social activities:

*"It was really good. They came to my house to see me, they asked me how I was, how it was going. When I was in a state, for example when I could not take the patients' transport alone, they helped me, came with me in the vehicle. They gave all the support they could, but it was too little, the whole thing closed down."*

*(Woman, 36, Hungary)*

Stakeholders stressed the importance of self-help groups, and expressed their regret that Bulgaria, Hungary, Latvia and Romania did not have strong user-led initiatives. Where self-help groups are in place, stakeholders noted that they provided a valuable alternative to public services. They offer community programmes such as arts and craft making and other social events, as well as transport support, mentoring and training sessions that raise the quality of life. Stakeholders in the United Kingdom proposed establishing user-led crisis houses that would provide an environment conducive to well-being and recovery.

## 2.4. Participation in the community

Participation and inclusion in community life is fundamental to independent living. This section will examine the experiences of people with mental health problems with peer advocacy and their participation in public and political life.

### Promising practice

#### Building capacity

Since 2009, Latvian NGO RC ZELDA has organised regular capacity-building meetings, in which 10–15 people with mental health problems discuss issues of importance to them, such as: access to social services; access to out-patient mental healthcare; the rights provided by the CRPD; the new Law on the Rights of Patients (2009); and what reasonable accommodation means in education and employment. RC ZELDA published a handbook in 2010 on peer advocacy for users of mental health services. The NGO plans to conduct train-the-trainer courses on peer advocacy to facilitate more active participation by people with mental health problems in advocacy.

*For more information, see: <http://zelda.org.lv/psihiatrijas-pakalpojumu-lietotaju-kapacitates-celsana> and the Handbook for users of mental health care services 'Peer helps peer' (Rokasgrāmata psihiatrijas pakalpojumu lietotājiem 'Līdzīgs palīdz līdzīgam'), Riga, RC ZELDA, p. 63, available at: <http://zelda.org.lv/wp-content/uploads/Rokasgramata.pdf>.*

The FRA report on the right to political participation shows that deprivation of legal capacity can result in the loss of the right to vote.<sup>108</sup> Among the EU Member States where interviews were conducted only Sweden and the United Kingdom permit persons with mental health problems to participate fully in the electoral process. Despite the restrictions in place elsewhere, none of the respondents commented on the issue of their right to vote.

Across the EU, self-advocacy groups have sought to influence government policy making related to persons with mental health problems. Such campaigns can serve as a vehicle for people with mental health problems to become involved in the political life of their communities. In several countries, self-advocacy groups have organised particular events to lobby for changes in government policy. In Romania, for instance, members of NGOs picketed the National Insurance Agency (*Casa Nationala de Asigurari*) and the Ministry of Health (*Ministerul Sanatatii*) demanding a debate be held on amending the law on mental health. With the help of the Ministry of Justice (*Ministerul Justitiei*), representatives of the Ministry of Health accepted an amendment to the article that allows hospitals to notify families within 72 hours of when a person with mental health problems is admitted to the emergency department.

Respondents in all countries were aware of the existence of organisations to support participation in community life. The level of participation in such groups varied considerably, however, as did awareness of the support they could provide. Respondents in Bulgaria,

<sup>108</sup>FRA (2010).





Greece and Romania did not have contact with groups involved with protecting the rights of persons with mental health problems and were unaware of how they could join such organisations.

### Promising practice

#### Focusing on peer advocacy

In Scotland, **United Kingdom**, the collective advocacy organisation Highland Users Group has established a project to challenge the stigmatisation of mental health problems and to raise awareness and understanding of mental health issues. The project involves: supporting mental health service users to speak out about their lives; delivering user-led mental health awareness training to professions such as psychiatrists, social workers and teachers; media and public relations work to increase public understanding and to challenge negative reporting on mental health issues; and the sharing of good practice in user-involvement and anti-stigmatisation work throughout Scotland and Europe.

For more information, see: [www.hug.uk.net/challengestigma\\_home.htm](http://www.hug.uk.net/challengestigma_home.htm)

The level of development of peer advocacy organisations was closely linked to participation in public and political life. In France, Germany, Sweden and the United Kingdom several of the respondents were involved in service user groups which articulated the perspective of people with mental health problems in order to influence policy and service delivery. They referred to well-developed networks of advocacy groups which sought to involve people with mental health problems in the design and implementation of policies and services affecting them. In contrast, in Bulgaria, Latvia and Romania respondents discussed the lack of self-representation groups or organisations for people with mental health problems, and in Hungary stakeholders reported an almost total absence of advocacy groups.

*"I miss some newspaper, newsletter or something which would reflect the problems and the potential of persons like me. I would like to be involved in preparing such a newsletter, issued for example by the day-care centre I use now."*

(Woman, 51, Bulgaria)

Stakeholders generally recognised the importance of self-advocacy groups and suggested that such groups and organisations should be more involved in influencing the content and delivery of care. Stakeholders in Hungary identified the scope for user-led groups to empower and inform people:

*"One possible way to tackle people being treated as children is self-help groups as these communities can significantly improve the motivation of the persons concerned to make decisions on their own and govern their own lives."*

(Stakeholder, Hungary)

Stakeholders also stressed the need to build up the capacity and presence of advocacy organisations while maintaining their political independence.

*"When we talk about the situation of persons with mental health problems their problems should not be presented by us anymore but by them. The face of these people is lacking in the media and in our society."*

(Stakeholder, Bulgaria)

*"Our members do not have money to travel so that we can see each other to discuss even our agenda. The communication between us is broken. Some suggest that we use Skype but others do not want or do not have Skype. So we need support to be able to work as an organisation."*

(Stakeholder, Bulgaria)

## 2.5. Barriers to inclusion and participation

This section examines experiences of participants in regard to barriers to inclusion and participation in the community, including restrictions of legal capacity and guardianship; informal restrictions on decision-making; issues of involuntary treatment and involuntary placement; past experiences in institutions; stigma and discrimination; difficulties in accessing justice; and, financial restrictions, including poverty and the impact of austerity measures.

### Restrictions of legal capacity and guardianship

A variety of legislative provisions in the countries covered by the research regulate the deprivation of legal capacity, as well as the appointment and functions of a guardian affecting different aspects of people's choice and control over their lives. A legal analysis of the situation in the EU is provided in a forthcoming FRA report.<sup>109</sup>

At the time of the research only a few respondents were under different forms of guardianship and some others had previously experienced it. In addition, a third of French respondents were under curatorship and a small number of Swedish respondents had mentors: curators and mentors can make legally binding decisions only with the agreement or consent of the person concerned.

<sup>109</sup> See FRA (forthcoming).

The respondents' experiences of the process of entering into guardianship varied widely. One woman in Germany spoke positively about the process and her involvement in it:

*"Someone from the court came [...] and then I chose her (the guardian) myself [...] she had a file with her too, well, I do think it works well."*

(Woman, 50, Germany)

In Sweden, a participant explained that he had requested a mentor and was able to choose one that he liked.

By contrast, respondents in Bulgaria, Hungary, Latvia and Romania said that they had not understood what was happening when the restriction of their legal capacity was considered or what the implications of being placed under guardianship would be. One Bulgarian man was sedated before being taken from hospital to the court hearing:

*"I was sleepy and they did not try to explain anything to me."*

(Man, 41, Bulgaria)

One Hungarian woman was convinced that she was under guardianship, although in fact she retained full legal capacity:

*"My mum has been my guardian for three years now and really if mum doesn't have time to come with me and I go to the psychiatric hospital on my own then the doctor complains right away saying that I should not do this because my mother has to come as well so I should not do this. Also, if here in the local hospital, they advise that I should stay [...] they always need my mum to sign so that she approves of me being admitted to the hospital."*

(Woman, 27, Hungary)

Some respondents said that guardianship proceedings were initiated following disputes with family members:

*"We had quarrels with my mother before the hospital. She made my Roma girlfriend have an abortion in the village where we lived with her. [...] I wanted the child but she told me I am not ready to have a child. [...] I was angry because I did not know. [...] My mother brought my girlfriend to the place and paid for the abortion. [...] So they punished me with compulsory treatment [...] while I was in the hospital she became my guardian."*

(Man, 41, Bulgaria)

A number of respondents had negative experiences with guardians. For example, one respondent in France was unhappy because his curator restricted the budget he was allowed to spend supporting a heavy smoking habit. Another said that having his family as

curator placed a lot of strain on family relations. Others, who had no experience of guardianship themselves, expressed concern about the impact it could have on their autonomy:

*"A guardian, that would be the worst thing I could imagine."*

(Woman, 52, Germany)

On the other hand, two respondents in Sweden had positive experiences with their mentors regarding their choice and control over day-to-day living. They said that the arrangement provided them with useful support, such as in managing their finances.

## Informal restrictions on decision making

Respondents spoke about a number of informal restrictions on their ability to take decisions about their lives. Although in many cases, as discussed previously, families were an invaluable source of support, some respondents said that their families restricted their choices, especially when they depended on them financially:

*"My 'dad' influences me in many things, he supports me financially, and due to that – how to say that, doctor – he does not let me [...] be independent [...] be myself. I am under his influence. If I do not obey, he threatens me with taking back the support from my children. This is a terrible situation; I simply cannot assert myself."*

(Woman, 36, Hungary)

*"But there are some people who are manipulative, for example a friend of mine lost her property that way. She was pushed over the edge by people telling her to go to different places all the time. She was physically and emotionally exhausted. Afterwards all her relatives got together and told her 'Now sign these papers'. And she signed. Now she lives in a social care institution."*

(Woman, 26, Latvia)

In one case, a respondent was allegedly exploited:

*"While I was at home, she always tried to control my money and asked me to sign a power of attorney and she received my money and did not give me money [...] and she bought my sister a car with the money I received. For more than a year she received the money."*

(Woman, 47, Latvia)

Other respondents described how their parents tried to influence their choices about relationships and having children. A respondent in Romania, for instance, said that her parents pressured her into following a psychiatrist's recommendation that she have an abortion because of her mental health problems.





## Financial problems

Low income and reliance on benefits are significant factors that can limit the choice and control persons with mental health problems have over their lives.<sup>110</sup>

*“I want to live by myself but just cannot afford this now.”*

(Woman, 31, Bulgaria)

Poverty and mental health problems are self-reinforcing phenomena. A survey by Eurobarometer in 2010<sup>111</sup> showed that it is the poorest in society who suffer the most from mental health problems. The income of more than half of the respondents came from benefits or a disability pension. Respondents in Bulgaria, France and Germany and stakeholders in Greece explicitly cited poverty as a major factor inhibiting inclusion and participation:

*“The benefit provided by the state is at one third of the poverty threshold. So practically, the right to independent living [...] does not exist.”*

(Stakeholder, Greece)

*“If you have money troubles added to your mental health problems, you are in a precarious position.”*

(Man, 44, France)

Participants mentioned financial problems in a variety of contexts. In Greece, Romania, Sweden and the United Kingdom, participants were concerned about changes to the benefits systems and cuts in provisions. In Bulgaria, they were worried about the frequency of their disability status review as they could not receive a disability pension until they have been reviewed.

The sole income of those respondents without paid work came from benefits supplemented by financial help from family members:

*“In the beginning we managed on our own with paying for those utilities [expenses], food. Last year we managed, but this year [...] heating is very expensive, so my mother helps me materially a little bit.”*

(Woman, 25, Latvia)

Lack of financial resources also meant that respondents could not afford to engage in cultural and leisure activities unless they were subsidised, funding for which the economic crisis has apparently curtailed:

*“Before, I used to go to the cinema, exhibitions and theatre a lot, but now I cannot afford to pay for it. They used to take us to such events from our centre but they haven’t done so during the last year.”*

(Woman, 51, Bulgaria)

*“I used to play sports. I used to go to the cinema every two weeks. I stopped doing that because I couldn’t afford it. I don’t do either of those now. I watch the television sometimes.”*

(Man, 45, United Kingdom)

A respondent in the United Kingdom highlighted a lack of information about existing subsidies:

*“There are schemes locally where they give you free training sessions with somebody at the gym if you need help. But nothing is freely advertised: you get some discounts and bus passes – nothing is advertised. You hear of them from somebody else.”*

(Woman, 32, United Kingdom)

In contrast, respondents in Romania said that, provided they had a disability assessment certificate, they enjoyed free access to theatres and museums.

## Involuntary treatment

Various legislative provisions regulate the possibility for involuntary psychiatric treatment. The FRA report *Involuntary placement and involuntary treatment of persons with mental health problems* analyses the legislation in place across the EU and, in addition, the findings in regard to involuntary placement or treatment from the fieldwork interviews with persons with mental health problems. All EU Member States specify minimum criteria for involuntary treatment and provide for a right to appeal against placement or treatment decisions. Despite these safeguards, however, respondents described their experiences of involuntary treatment in overwhelmingly negative terms, characterising them as frightening and humiliating. Specifically, respondents said that they were not provided with an explanation about the treatments and were given no opportunity to discuss them with their doctors.

## Impact of experiences in institutions

A number of respondents reflected upon their past experiences in psychiatric hospitals, although, as already mentioned, people currently living in psychiatric facilities were not interviewed. Thus, all the accounts presented here relate to past events – some occurring in the last year but others stretching back over a period of decades. When recounting past experiences in institutions, respondents spoke of isolation, lack of privacy, the rigidity of daily routines, and power inequalities between staff and patients. Stakeholders were also critical:

<sup>110</sup> For more information see European Commission (2008d).

<sup>111</sup> European Commission (2010) *Mental Health*, Special Eurobarometer 345/Wave 732 – TNS Opinion & Social, October 2010, available at [http://ec.europa.eu/health/mental\\_health/docs/ebs\\_345\\_en.pdf](http://ec.europa.eu/health/mental_health/docs/ebs_345_en.pdf).

*“Our experience with attempts to communicate with patients placed under treatment in our regional hospital showed that it is very inaccessible for outside people. The overall condition of the patients in terms of their rights is worse than the condition of [...] prisoners. Their contact with relatives and friends is [...] cut, their phone[s] [are] taken away and the visits of outside people are not allowed.”*

*(Stakeholder, Bulgaria)*

Respondents who had lived in institutions in the past spoke of an overwhelming feeling of lack of privacy caused by a dearth of personal space because, for instance, they shared rooms and bathrooms with others, sometimes with many others:

*“Dark rooms, very small spaces, always a stale and foul odour. The bed sheets were dirty. There was no place [...] to take a bath, and toilet bowls were cracked.”*

*(Woman, 39, Romania)*

*“All the patients had to use the bathroom together.”*

*(Man, 55, Greece)*

*“We slept two persons in a bed [...] it was stupid, like in a concentration camp.”*

*(Man, 43, Bulgaria)*

Respondents also expressed discomfort at the sense of being watched and said they considered staff surveillance intrusive:

*“Sometimes what they used to do was ‘obs’ where they watched people all day long. It was like a prison cell. They’d have the window like in a prison cell. They’d watch.”*

*(Woman, 45, United Kingdom)*

In the United Kingdom and Hungary respondents spoke of glass doors in wards as having a particularly negative effect on women, who were made to feel vulnerable and exposed. In Latvia, a respondent was disturbed by the close circuit television (CCTV) installed – with the exception of bathrooms – throughout the hospital.

Respondents in Bulgaria, Germany, Hungary and Sweden said that mobile phones were sometimes confiscated during hospital stays:

*“As soon as they noticed my telephone, they took it. It was simply not allowed to use the telephone. Then I had to give it to the storekeeper, and it was awful.”*

*(Woman, 36, Hungary)*

In Romania respondents said that they were not permitted to use mobiles in closed wards, but could use them in open ones.

In Bulgaria, a psychiatrist who worked in a psychiatric hospital provided one explanation of why patients were not permitted to keep mobile phones:

*“We had a patient with [a] high position in society and some of the other patients used a mobile phone to [photograph] her and to send the pictures to be uploaded [on] the internet. We have to protect her rights and this is why we do not allow patients to use mobile phones.”*

*(Stakeholder, Bulgaria)*

In contrast, a respondent in Sweden who had spent time in a psychiatric hospital said that the staff had bought cheap mobile phones, without a camera function, for all patients so that they could keep in better contact with their friends and family without risking the privacy of other patients.

Respondents also often spoke of their frustration with the number of restrictions on aspects of daily life and rigid routines:

*“There are restrictions everywhere, what you do, how you express yourself, restrictions everywhere. You cannot go out, you cannot say the wrong thing.”*

*(Woman, 26, Latvia)*

They also referred to restrictions on where they could go and access to the outdoors.

*“You stay alone in a room, in pyjamas, you are not allowed to go out, as these are the conditions in the hospital.”*

*(Woman, 39, Romania)*

In Bulgaria, a respondent described how she helped staff in order to be allowed outside for a few minutes:

*“Once a doctor in [...] did not allow me to go out of the ward (usually ... we cleaned the hospital, the corridors, rooms, windows, and as a reward after that we were allowed to go out). Big deal that they would allow you to breathe fresh air for 10 minutes or half an hour!”*

*(Woman, 48, Bulgaria)*

Respondents also regarded regulations affecting other aspects of choice and daily living as unnecessary or overly bureaucratic:

*“There was a person who kept the cigarettes, but the rest of the cigarettes were kept by the storekeeper, but you had to ask for each one from the storekeeper, then you had to give it to the nurse, and then you gave it to – how do you say that – to the other person who stored the cigarette, so the whole thing was dreadful.”*

*(Woman, 36, Hungary)*



Respondents recalled a number of limitations on choice and control over their personal hygiene. In Bulgaria, respondents said that they were not allowed to go to the toilet when they needed to. In France, a 39-year old woman described how, after being involuntarily admitted to a hospital in 2009, as punishment for breaking a window she was denied a shower.

Many negative experiences with staff related to their use of seclusion or restraint. Some of the respondents had experienced such seclusion or restraint themselves and others had witnessed forcible restraint being practiced on others. In the United Kingdom, a respondent described being secluded overnight in a room naked without bedding or furniture; a French respondent reported a similar experience. The use of forcible restraint was described by all who had experienced it as a traumatic and unforgettable experience that caused some of them physical injury:

*“And because I resisted they tied me to the bed. It was horrible, awful! That was hard on a person. To tie you up to the bed so tightly you cannot move. And I asked for a drink, there was one person there, it was night time, and I was left alone in the corner moaning. And so I lay there in the dark, one orderly showed up and I asked her for a drink, and she brought a glass of water and I asked – can she untie one of my hands? Then she poured the glass of water in my face.”*

(Woman, 53, Latvia)

*“The last time there were two women and three men [...] the men were very firm and aggressive. [...] It is only one woman who looked me in the eyes in this traumatic moment. [...] I think they ought to give the patient a feeling of having control, even in such a miserable moment. It is humiliating to be put in belt restraints on a plank bed with your legs spread; not even Jesus was crucified with his legs spread!”*

(Woman, 42, Sweden)

*“Restraint, that was very traumatic because there was no debriefing and the whole process of restraint, er, in my eyes it was bad.”*

(Man, 56, Germany)

*“One person was chucked in his bed. He was really chucked like that, his arms were held down, they tied him, strapped him, and I don’t want to know what else they did. However, he did not do anything bad; he was just talking at the window. There was nobody there though.”*

(Man, 40, Hungary)

*“I didn’t like the fact that sometimes the patients were strapped down. The staff should not have tied them down to calm them. They should have talked to them. This made me sad.”*

(Man, 36, Greece)

Some of the respondents considered that ethnic origin, age, sexual orientation and class affected the way staff treated patients:

*“In one instance there was a lady brought in to the hospital who was not treated very well because she was not very clean and also I think because she was a Roma.”*

(Woman, 27, Hungary)

*“Well, unfortunately it happened a couple of times that there were elderly men on the closed unit where I was, and the staff treated them like dogs, they talked to them in a way, in an awful way.”*

(Man, 40, Hungary)

*“I was pressed up against the wall by a male nurse, who said he did not like me hinting at my sexual orientation.”*

(Woman, 42, Sweden)

*“The staff treated me differently because they perceived me as being reasonably middle class. Somebody I’m still good friends with, we were both at one stage, suicidally depressed. She had ECT treatment and I didn’t. I was referred for talking therapy and afterwards I actually wrote to the consultant – I said ‘why did you send me for therapy and not my friend who you sent for ECT?’ And the reply came back: ‘We didn’t think that she would take to talking therapy.’ It was a different judgment about me. I’ve always been a good talker and speaker, I’m a very verbal person. But that other person now has early Alzheimer’s and she’s not much older than me. She was put on some very strong drugs which I avoided because I talked myself out of Librium and stuff like that, because I didn’t like the sound of it. Whereas she was not able to do so and she was put on these terrible drugs and she’s now a mass of physical problems. And I think I avoided the worst treatments simply because of my social class and my education.”*

(Woman, 55, United Kingdom)

In Latvia and Hungary stakeholders attributed problems with staff behaviour to lack of adequate training, staff shortages and heavy workloads. A respondent in Hungary, when asked whether she thought the lack of attention given to patients arose from lack of staff training, expertise or time said:

*“Well, I think it is the matter of time, because they do not have the time, so they walk by the patients, no matter if they ask for a glass of water and so on. So yes, it’s a matter of time.”*

(Woman, 34, Hungary)

## Stigmatisation and discrimination

Across the EU legislation transposing the Equality Employment Directive<sup>112</sup> prohibits direct and indirect discrimination, as well as harassment and any instruction to discriminate on grounds of disability, religion and belief, age, and sexual orientation in the fields of employment and occupation, vocational training and membership of employer and employee organisations.

Nevertheless, discrimination remains part of the everyday lives of people with mental health problems across the EU, particularly in the area of employment, as discussed previously. A survey carried out by the Academic Society of Romania shows that of those who reported being discriminated against, 30 % say it related to the labour market.<sup>113</sup>

### Promising practice

#### Combating stigmatisation and discrimination

National Mental Health Week in **France** aims to raise awareness through grass-root actions. Each year in March more than 400 events take place with users, carers, professionals, local officials, the media and the general public taking part. The week aims to open public debate on mental health issues, promote public information, raise the awareness of stakeholders and elected officials, encourage people to seek help and fight against the stigmatisation of persons with mental health problems.

In **Greece**, the University Mental Health Research Institute (UMHRI) (*Ερευνητικό Πανεπιστημιακό Ινστιτούτο Ψυχικής Υγιεινής, ΕΠΙΨΥ*) and the Greek Ministry of Press published a guide for the presentation of mental health topics in the media. The manual focuses on providing accurate and objective information on mental health topics and refuting common myths and prejudices, particularly through the use of correct and socially responsible language. 'Neutral' terms are suggested to replace commonly used stigmatising labels. The guide also aims to raise awareness among media workers of the consequences of stigmatising, and in highlighting the role the media can play in either perpetuating or combating such stereotypes.

For more information on France, see: [www.unafam.org](http://www.unafam.org) and [www.psycom75.org](http://www.psycom75.org); and on Greece, see: [www.epipsi.gr/Service\\_all/Service/Antistigma/](http://www.epipsi.gr/Service_all/Service/Antistigma/)

Participants from Bulgaria, France, Germany, Greece, Romania and the United Kingdom recalled being victims of stigmatisation, abuse or bullying. Respondents and stakeholders recognised that there were entrenched misconceptions about people with mental health problems which contributed to stigmatisation and reduced opportunities to participate in society. These misconceptions often resulted in fear of people with mental health problems, leading to their social isolation, particularly in rural areas. According to a Eurobarometer survey in 2010, on average, 22 % of EU citizens would find it difficult to talk to a person with a significant mental health problem, and a further 11 % are not sure how they would react.<sup>114</sup> Many respondents commented on the negative effects of stigmatisation on their personal and family relations.

*"With the illness it was like this: I was practically excluded from the family."*

(Woman, 52, Germany)

*"My family rejects me just because I was in that psychiatric hospital."*

(Woman, 47, Latvia)

*"I had a boyfriend whom I met after I finished high school. I did not tell him I had a crisis in 1999-2000. In 2005, when I had the second crisis, he realised I had it as he came to the hospital and talked to my doctor. After that he gradually stepped away from our relationship and we parted. He said his parents influenced his decision and [used] my illness [to justify their role]."*

(Woman, 29, Bulgaria)

Given the stigmatisation associated with mental ill health, respondents avoided disclosing their mental health problems wherever possible. A stakeholder in Bulgaria explained how people would travel long distances to be treated away from their home town to hide their condition:

*"There is a group of patients who do not search for psychiatric care in their places of residence for a number of reasons. I have patients from very distant towns. They come to Sofia because in Sofia they are anonymous. They say that the provision of psychiatric help to them in the small town would be known by the whole town."*

(Stakeholder, Bulgaria)

Respondents also mentioned incidents of abuse. In Latvia, a woman respondent describes the hostility she regularly encounters from a bus driver to whom she shows her disability card:

<sup>112</sup> Council Directive 2000/78/EC, OJ 2000 L 303.

<sup>113</sup> Academic Society of Romania, *Diagnostic: excluded from the labour market. Impediments in the employment of disabled persons in Romania*, available at: <http://observator.sas.unibuc.ro/wp-content/uploads/2011/01/Diagnostic-exclus-de-pe-piata-muncii.pdf>.

<sup>114</sup> European Commission (2010) *Mental Health*, Special Eurobarometer 345/Wave 732 – TNS Opinion & Social, October 2010, p. 61-62, available at [http://ec.europa.eu/health/mental\\_health/docs/ebs\\_345\\_en.pdf](http://ec.europa.eu/health/mental_health/docs/ebs_345_en.pdf).



*“When I show him the card, he starts yelling so the whole bus can hear him: ‘The invalids are here, again those invalids!’”*

(Woman, 25, Latvia)

In the United Kingdom all respondents who had attended mainstream schools reported being bullied there, as did over half of those attending special schools. They also said that they had been verbally abused in the street and on public transport, and many had been subject to attacks on or in their own homes. Although most participants were aware that certain actions were wrong and against the law, not all were convinced that the law could adequately protect them. Respondents in Germany felt that there was inadequate protection from victimisation, particularly in relation to making complaints.

## Difficulties in accessing justice

There are a variety of measures in place across the EU to enhance the opportunity for persons with mental health problems to access justice. In Germany, for instance, the Federal Network of Independent Offices for Complaints on Psychiatric Services (*Bundesnetzwerk unabhängiger Beschwerdestellen Psychiatrie*) established in 2010 operates in nearly 50 regions.<sup>115</sup> These offices investigate grievances and complaints regarding psychiatric services, provide assistance and mediation services and try to find remedies. In France, the post of ‘general inspector’ of deprivation of liberty sites (*Contrôleur général des lieux de privation de liberté, CGLPL*)<sup>116</sup> was introduced in 2007.<sup>117</sup> This office can either offer its own services or be called upon by authorised persons or organisations. In cases involving the violation of fundamental rights, the CGLPL can demand a response and/or refer the case to the public prosecutor or to the relevant disciplinary bodies. The CGLPL also advises on legislative changes.<sup>118</sup>

Nevertheless, many practical obstacles continue to inhibit access to justice. This is particularly problematic in institutions. The Bulgarian Helsinki Committee reported, for instance, that residents in institutions and psychiatric patients in acute wards do not have free access to pen, paper or envelopes nor to a post office, telephone or internet to send a complaint to

the relevant authorities.<sup>119</sup> Research conducted by the Latvian Centre for Human Rights in 2006 indicated that 43 % of patients in psychiatric hospitals and 27 % of social care home residents did not know where to seek assistance to make a complaint about the quality of medical care, the attitude of personnel or conditions at psychiatric facilities.<sup>120</sup>

Respondents spoke of considerable discrepancies in terms of their awareness and use of complaint and redress mechanisms. In Germany, respondents active in self-help organisations were, for instance, familiar with the institutional complaints bodies such as patient advocates, local, regional and federal offices, residential home advisory boards and workshop councils, but other respondents relied on their relatives and existing networks and service employees and some had no knowledge of complaints procedures. In Bulgaria none of the respondents was aware of complaints mechanisms in psychiatric hospitals.

In Greece, the majority of the respondents said that they had been informed of their rights with regard to bad or unfair treatment or bullying and harassment. They were aware of the competent institutions and the option to submit complaints; they pointed in particular to the Greek Ombudsman as the main institution protecting human rights. A few respondents said, however, that they feared ‘publicity’ and stigmatisation if they addressed the ombudsman.

Few participants had made a formal complaint or taken legal action. In France, Hungary and Sweden a small number of participants had instigated legal action against official bodies or service providers. Only in the United Kingdom, where three-quarters of participants had complained about aspects of their treatment, had a majority accessed justice.

## Summary

The extent to which people with mental health problems interviewed were able to live independently in the community varied considerably reflecting the different degrees and types of support available to them. Although considerable progress has been made, much more remains to be done. Disabling obstacles and processes – ranging from long, and sometimes involuntary, stays in psychiatric hospitals, restrictions of legal

<sup>115</sup> See: [www.beschwerde-psychiatrie.de/index.html](http://www.beschwerde-psychiatrie.de/index.html).

<sup>116</sup> France, *Projet de loi relatif aux droits et à la protection des personnes faisant l’objet de soins psychiatriques et aux modalités de leur prise en charge. Etude d’impact*, May 2010, p. 15.

<sup>117</sup> France, *Loi n° 2007-1545 du 30 octobre 2007 instituant un Contrôleur général des lieux de privation de liberté. Journal officiel de la République française*, 31 October 2007.

<sup>118</sup> Stark, J. and Mauguey, C. (2009) *Droit et hospitalisation psychiatrique sous contrainte*, Paris, L’Harmattan, p. 42-43.

<sup>119</sup> Bulgarian Helsinki Committee (2011) *Human rights in Bulgaria in 2010*, Sofia, Bulgarian Helsinki Committee, available at: <http://issuu.com/bghelsinki/docs/report2010-english>.

<sup>120</sup> Leimane-Veldmeijere, I. and Veits, U. (2006) *Needs Assessment of Users of Mental Health Care Services*, Riga: Latvian Centre for Human Rights, available at: [www.humanrights.org.lv/html/news/publications/29057.html](http://www.humanrights.org.lv/html/news/publications/29057.html), p. 21.

capacity and financial pressures to a lack of reasonable accommodations at work, insufficient support services, and stigmatisation and discrimination – contributed to excluding them from community life. Still, the interviews also showed evidence of promising practices that help people with mental health problems to exercise more choice and control over their lives. Respondents described being empowered by appropriate support and accommodative systems, while reflecting on restrictions that undermine their autonomy.

A lack of meaningful choice and control over where to live remains a dominant issue for people with mental health problems. Although many respondents lived alone or with people they have chosen, giving them both control over their daily lives and a place of refuge, others have not achieved this due largely to two inter-related factors. First, the lack of appropriate housing in the community and support for independent living leaves many with little choice but to live with their families or in group-based accommodation characterised by varying degrees of institutional culture. Second, low income levels and dependence on state benefits restrict opportunities to choose a home to rent or buy. Participants also described the lack of choice over which area to live in associated with reliance on subsidised housing. While none of the participants lived in institutions, many expected that they would again spend time in psychiatric hospital in the future, and were concerned about the impact it would have on their ability to live independently in the long term.

Insufficient autonomy and inclusion can also curtail the ability to make choices over daily life. While many complete basic education, the onset of mental health problems during late adolescence often interrupts university education. Combined with a lack of reasonable accommodations and on-going discrimination on the part of employers, this serves to undermine employment prospects. In the absence of opportunities on the open labour market, many seek – or are given – jobs in sheltered workshops or are engaged with voluntary organisations, viewing these activities as offering the interaction, feeling of contributing to society and sense of purpose they would ideally get from paid work. Periods spent at sheltered workshops, however, serve to segregate people with mental health problems from mainstream community life and can create stigmatisation that further undermines their prospects of getting and maintaining paid work on the general labour market.

Away from work, difficult interactions with healthcare services and insufficient or inappropriate community-based mental health support often cloud daily life. General practitioners frequently fail to take physical complaints seriously, assuming that somatic issues are

related to mental health status. Similarly, treatment for physical illness can be restricted on the basis of mental health problems, while information about diagnosis, medication and potential side effects is often lacking. Where available, talking and non-medical therapies, as well as local centres offering flexible support and varieties of activities are highly prized. Respondents reflected on the need to enhance the availability of and access to such services, and particularly on the importance of ensuring that they reflect the fluctuating nature of mental health problems.

To live independently and have genuine choice and control over their lives, people with mental health problems are likely to require access to a range of different forms of support. In terms of formal support, assistance with the development of independent living skills can smooth the transition from institutional or family living arrangements to community-based ones. In the community, state-funded advocates or agents, who provide particular services such as support with finances, are highly valued. Others can benefit from technical devices, and from self-developed techniques to avoid difficult tasks during periods of mental ill-health. Informal support mechanisms also serve to facilitate autonomy and inclusion. Discussing issues and getting informal advice from family and friends before making important decisions was identified as a key source of support by many participants, as were representative and self-advocacy organisations, which often offer services and practical assistance with navigating different support options alongside their peer-support role. Where such support mechanisms are lacking, exercising choice and control over daily life can become more challenging. Concern about the limited – and sometimes declining – availability of many support options emerges strongly as a theme of this research.

In some countries, representative and self-advocacy organisations play a valuable role both through peer support and by giving a voice to people with mental health problems in processes of shaping service delivery and policy. Where strong networks of user-led organisations exist, they can help to inform and empower people with mental health problems, giving them both awareness of their rights and a means through which to articulate and campaign for their needs. In other countries, however, such organisations face considerable challenges in terms of capacity-building or political environment, leaving people with mental health problems more isolated, unsupported and less able to influence the shape of policies affecting them.

Alongside the challenges to autonomy and inclusion associated with living arrangements, daily activities, support services and participation in the community, additional legal and societal barriers work to curb the





choice and control people with mental health problems can exercise over their own lives. On the legal side, many people are formally deprived – either totally or in part – of their legal capacity. This can leave them unable to sign contracts for employment or to take decisions about their property and finance, with these choices instead made by guardians they often have not been able to choose themselves. This lack of decision-making power is particularly acute in relation to involuntary placement or treatment, which can see people with mental health problems detained and treated in residential care against their will. Informal restrictions on legal capacity are also powerful, with families sometimes acting to restrict people's choice and control, and interfering excessively in their private lives. Moreover, despite changes intended to make the legal systems in EU Member States more accessible and responsive to people with mental health problems, many obstacles continue to restrict access to justice. Lack of awareness of complaint or redress mechanisms, insufficient legal support and fear of stigmatisation mean few people make formal complaints.

Societal barriers include institutional regimes that limit the choice and control not only of those in psychiatric hospitals and large social care homes, but also in smaller group homes where institutional cultures persist. Participants recalling their time in institutions described them as characterised by a lack of privacy and regimented daily routines, and marked by unequal power relationships between staff and residents. In the community, stigmatisation and discrimination on the basis of mental health are common occurrences. Entrenched misconceptions about people with mental health problems lead to abuse and bullying from the public, as well as sometimes negatively affecting personal relationships and interaction with service providers and medical professionals. This contributes to social isolation and reduced opportunities to participate in society. Fear of possible recriminations means, in addition, that many choose not to disclose their mental health status to others, depriving them of the possibility to benefit from reasonable adjustments.

Finally, economic factors operate to exclude and marginalise people with mental health problems and deny them access to opportunities on an equal basis with others. In the absence of paid employment, many people are reliant on benefits, often set at a low level, for all or most of their income. Low income levels limit choices about where and with whom to live, to restrict access to support and to curtail participation in activities that would enable greater inclusion in the community. Such dependence exacerbates the stress brought on by repeated changes to the benefit system or to entitlement thresholds, as well as anxiousness associated with the need to prove the severity of mental health problems in order to renew one's disability status. Added to cuts in services and social security benefits associated with on-going austerity measures, this precarious financial position creates an insecurity that risks holding back progress towards meaningful independent living.



## Conclusions

The findings demonstrate that many of the participants in this research often had reduced opportunities to live independently and participate in community life. The results also illustrate the positive impact that reform processes are already having on the lives of persons with mental health problems and those with intellectual disabilities. By highlighting some of the promising steps that are being taken to promote the choice and control they have over their lives, and by giving a platform to those whose voices are seldom heard, this report provides an in-depth understanding of the current situation which serves to illuminate the informed discussion that should now take place within the EU.

Despite important differences between individuals, many of the limitations which restrict independent living opportunities affected both people with mental health problems and people with intellectual disabilities. These limitations result largely from the persistence of disabling barriers which operate to exclude them from the mainstream of community life. The personal cost of practices of disempowerment, segregation, neglect, hostility and discrimination that were described by the individuals whose voices permeate this report is incalculable. When, however, accommodative policies and adequate support were in place, participants spoke of the autonomy and freedom such measures brought to their lives, and reflected on the inclusion and participant in community life that opened up to them.

Individuals striving to live independently in the community need an enabling community context. The findings of the research point to a number of dimensions of community life and service provision which need to be addressed in order to improve access to and enjoyment of community facilities and services such as healthcare, public transport, education and municipal authorities. This raises questions about the capacity of current community services – both in terms of finances

and human resources – to meet the needs of people with intellectual disabilities and mental health problems, particularly in the context of the economic crisis.

The main obstacles to independent life identified through the research include legislation and policies that fail to support autonomy adequately or prevent it; lack of adequate community-based housing and support options; persisting negative attitudes and low expectations which prevail in society, among many families, professionals and policy makers; and, wider socio-economic factors which limit the scope for exercising choice and control, including labour market disadvantage and low income.

Despite deinstitutionalisation efforts the continuing existence of large scale institutions and persisting institutional cultures contribute to the limitations of individual choice and autonomy. Leaving an institution often hinges on the availability of housing provision and other support in the community, making it difficult. People with disabilities cannot enjoy meaningful social inclusion and participation in the community without adequate support freely chosen and controlled by them.

Lack of encouragement, empowerment and opportunity to develop skills and independence can also impose constraints on the opportunities to live independently and participate in community life, even if they do not directly result in dependence on family members or others. Without adequate and independent income, appropriate support and integration measures, persons with mental health problems or intellectual disabilities may still face social isolation, even if they are physically located in a house or apartment in the community.

Stigma, hostile and negative attitudes contribute to the isolation experienced by many respondents. Such attitudes lead to discrimination affecting persons with

mental health problems or intellectual disabilities across all areas of social life, including employment, where strong legislation prohibits such phenomena. This situation is as unacceptable as discrimination on other grounds, such as race or ethnic origin, and shows that there is a need to provide broader protection against discrimination on all grounds including disability.

The analysis presented in this report reveals a number of key factors operating at the level of the individual, the family and society, the community context, and the legal and policy sphere, which shape the level of choice and control people with disabilities have over their lives.

At the individual level, respondents confirmed that having choice and control in their lives was essential to their sense of personal well-being and belief that they had a future. Although many had not achieved this, others had found a voice through peer contact and mutual support. Peer support, user-led organisations and self-advocacy groups in particular appear to have played an instrumental role in helping individuals to develop higher expectations and to recognise and challenge injustice.

Positive and supportive relationships with family members and others, including professional staff, were also important. Family members – whether parents, siblings or partners – are often a critical source of security and support for people with intellectual disabilities or mental health problems, especially in the absence of other community-based support. Nevertheless, legal and policy frameworks should ensure that persons with disabilities who live with their families retain choice and control over their personal lives.

The research revealed situations where a person has no alternative but to live in an institution because they or their families lack financial and other resources to support them at home. To avoid such situations, specific measures may be necessary to provide families with the necessary support to keep their family members with intellectual disabilities or mental health problems at home. These measures should encourage families to play a role in fostering education and employment expectations and in assisting in their relative's transition to independent living.

Discrimination in the labour market entrenches the dependence of people with intellectual disabilities or mental health problems. Their exclusion from the workplace is a major cause of poverty, which in turn limits the possibility to live independently and leads to wider segregation and isolation from the community. Such exclusion is also likely to have contributed to the hostility which people with intellectual disabilities or

mental health problems encounter when they do seek to engage with the wider community.

## The way forward

The rich vein of material provided by this research shows that although much has been done, more efforts are needed to ensure that persons with mental health problems and persons with intellectual disabilities can live independently and be included in the community. Key initiatives in policy, law and practice, such as those mentioned below, can facilitate progress helping persons with mental health problems and persons with intellectual disabilities to live more independently within the community.

- Legal and administrative measures to support decision-making by people with mental health problems or intellectual disabilities.

The deprivation of legal capacity can undermine the choice and control which is fundamental to living independently and being included in the community. The UN Committee on the Rights of Persons with Disabilities, in its Concluding Observations on Spain, recommended that “the State party review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences. It further recommends that training be provided on this issue for all relevant public officials and other stakeholders.”<sup>121</sup>

It is therefore worthwhile investigating how mechanisms other than those based on the substituted decision-making entailed in guardianship regimes can be established that can enable a person to negotiate important aspects of daily life, such as dealing with bank accounts or entering into financial transactions, which they might find challenging.

Laws on involuntary placement in psychiatric hospitals and involuntary psychiatric treatment should also be carefully assessed to ensure that they include the appropriate checks and balances to ensure ‘choice and control’ which is the basis of independent living and community participation. The UN Committee on the Rights of Persons with Disabilities has recognised the inconsistencies between such laws and the CRPD and recommended in its Concluding Observations on Spain that the State Party: “review its laws that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; repeal provisions that authorize involuntary internment linked

<sup>121</sup> United Nations, Committee on the Rights of Persons with Disabilities (2011), para. 34.



to an apparent or diagnosed disability; and adopt measures to ensure that health-care services, including all mental-health-care services, are based on the informed consent of the person concerned.”<sup>122</sup>

- Measures to ensure that adequate, good quality and freely-chosen personalised support for independent living is made available independently of the type of living arrangement.

Persons with intellectual disabilities and persons with mental health problems may need assistance, which can vary from person to person. This should be provided regardless of their living arrangement. Personal assistance and/or particular technical devices may be necessary to support independent living. Whatever the type of support, it is important to ensure that the user can choose and control its use. The provision of such valuable personalised support should not replace support and services provided by other important services and facilities, such as day centres.

- Measures to ensure that support is available to the families of children with intellectual disabilities or mental health problems and to parents with intellectual disabilities or mental health problems to enable them to look after their children.

Families often require additional support measures to ensure that a person with intellectual disabilities or mental health problems continues living with them. Without such support, there is a risk that the practice of abandoning such persons, in particular children, to institutional care will continue. Parents with disabilities may also require support to enable them to look after their own children at home. Such assistance should be freely chosen and controlled by the parents, and should adapt to reflect the families’ shifting needs as children grow older.

- Measures to enhance the financial independence of people with intellectual disabilities or mental health problems through social security and employment promotion programmes.

Without financial independence autonomy and choice cannot be achieved. Therefore, appropriate employment, sufficient income support and benefits and other relevant measures are necessary as preconditions for independent living, particularly during the current economic crisis – a point also recognised by the UN Committee on the Rights of Persons with Disabilities in its Concluding Observations on Spain.<sup>123</sup>

- Measures combating discrimination and ensuring equal access to employment and key areas of social life, such as education, culture, leisure and the provision of goods and services, including affirmative action to remedy existing inequalities.

The Equality Employment Directive<sup>124</sup> prohibits discrimination on grounds of disability in employment and occupation, vocational training and membership of employer and employee organisations. In addition, Article 5 of the directive requires that employers take measures to enable persons with disabilities to access, participate in, or advance in employment, or to undergo training (‘reasonable accommodation’). The directive, however, sets out minimum requirements and EU Member States may provide for a higher level of protection in national legislation. Indeed, robust laws to prohibit discrimination in areas beyond employment and occupation have already been implemented in some EU Member States, but enforcement requires more rights awareness efforts and support in lodging and following up complaints. EU anti-discrimination law could also be more effective by extending protection to all fields covered by the Racial Equality Directive.<sup>125</sup>

- Measures to develop appropriate community-based living arrangements that give a meaningful choice over where to live, making appropriate use of the EU’s structural funds.

Persons with mental health problems and persons with intellectual disabilities should be facilitated and empowered to choose where to live. This requires the development of and support for a range of different living arrangements that reflect their needs and wishes for different levels of support, including group homes, supported living arrangements and personal assistance in one’s own home. Such measures should ensure that people do not resort to living in institutions, simply because they have no other viable option. This need has been highlighted by the UN Committee on the Rights of Persons with Disabilities, which in its Concluding Observations on Spain expressed concern that: “[...] the choice of residence of persons with disabilities is limited by the availability of the necessary services, and that those living in residential institutions are reported to have no alternative to institutionalization.”<sup>126</sup>

EU Member States should make use of the EU’s Structural Funds for investments into deinstitutionalising mental health services and building up community-based services. As the European Commission’s Ad Hoc Expert Group on the Transition from Institutional to Community-based Care noted, projects which aim to build, enlarge

<sup>122</sup> *Ibid.*, para. 36.

<sup>123</sup> *Ibid.*, para. 9 and 39-42.

<sup>124</sup> Council Directive 2000/78/EC, OJ 2000 L 303.

<sup>125</sup> Council Directive 2000/43/EC, OJ 2000 L 180.

<sup>126</sup> *Ibid.*, para. 39.

or perpetuate institutions are not in line with the CRPD and the EU's own policies on equal opportunities, social inclusion and anti-discrimination, and should therefore not be eligible for funding. Member States should therefore ensure that structural funds are not used to build new segregating residential institutions.

- Measures to reduce any administrative burden associated with accessing and using public support services, including through the provision of accessible and relevant information, particularly regarding entitlements.

Processes to demonstrate eligibility and to apply for particular services should be as simple as possible, and clearly explained to persons with disabilities. In particular, information about and application procedures for support and services should be presented and communicated in ways that are accessible. This includes the preparation of easy-to-read material, as well as measures to ensure that information is provided when required. Choice and control over where to live also means being able to move to a different administrative area. This requires introducing a degree of flexibility to the way support, allowances and benefits are transferred from one area to another.

- Measures supporting the development of self-advocacy organisations and measures to increase the active participation and involvement in politics and in policy, in programme development and decision making by people with intellectual disabilities and people with mental health problems.

Involvement in social and political life is at the heart of the implementation approach required by Article 4 (3) of the CRPD. It reflects the fundamental demand of the disability movement: 'nothing about us without us'. To ensure such involvement, measures are needed to sustain and further develop the capacity of such organisations, particularly in those EU Member States where they are underdeveloped and to safeguard their existence and functioning, where public sector cuts put them at risk.

- Measures to support the establishment of more community-based mental health centres and services for persons with mental health problems.

Flexible, person-centred community-based centres and mental health services provide valuable support for independent living reducing the need for hospitalisation. It is important, therefore, particularly during a time of economic crisis and austerity-driven cuts to sustain such services.

- Measures to ensure the political participation of persons with mental health problems or intellectual disabilities. The right to vote is a basic prerequisite for effective involvement in the political process.

Laws which restrict the right of persons with mental health problems and persons with intellectual disabilities to political participation should be amended to ensure compliance with Article 29 of the CRPD, and the view of the Committee on the Rights of Persons with Disabilities that "all persons with disabilities, regardless of their impairment, legal status or place of residence, have the right to vote and participate in public life on an equal basis with others".<sup>127</sup> Additional steps that further facilitate political participation, for example allowing assistance by a person of one's choice and ensuring the accessibility of polling stations and election material, should also be considered.

- Measures to raise awareness about complaints mechanisms and to support people with mental health problems and people with intellectual disabilities to access justice and participate in judicial procedures.

Meaningful access to justice requires both awareness of available redress mechanisms and support to use them. More targeted steps should be taken to promote awareness of relevant legislation protecting the rights of persons with mental health problems and persons with intellectual disabilities and of the complaint mechanisms available independent of their living arrangements or legal capacity. Adequate, independent and accessible support should be provided to them throughout the legal process, including legal aid where necessary. Such measures should involve steps to increase the accessibility of the justice system, including by facilitating the participation of persons with mental health problems and persons with intellectual disabilities in judicial procedures.

Across the European Union the journey towards social inclusion and participation for people with mental health problems and people with intellectual disabilities has begun. There is still a long way to go and little time to lose. At stake are deep-seated values of the EU – a commitment to the dignity and autonomy of the person and an equal commitment to citizenship and inclusion.

<sup>127</sup> *Ibid.*, para. 48.





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# Annex 1: Sample composition at national level

Table A1: Sample composition – people with intellectual disabilities

Country	Total no. of interviews	Men	Women	Living arrangement			Education				Employment			
				Alone (with partner)	Protected/Group home	Family or friends	Compulsory/elementary	Secondary/High school	University	No education	Unemployed	Protected/sheltered	Open labour market	Other
<b>TOTAL</b>	<b>105</b>	<b>58</b>	<b>47</b>	<b>18</b>	<b>29</b>	<b>58</b>	<b>48</b>	<b>49</b>	<b>2</b>	<b>6</b>	<b>59</b>	<b>27</b>	<b>14</b>	<b>6</b>
BG	10	6	4	-	9	1	1	9	-	-	8	1	1	-
DE	10	5	5	1	5	4	9	1	-	-	-	9	1	-
EL	20	12	8	-	3	17	13	1	1	5	19	-	1	-
FR	10	6	4	6	-	4	5	5	-	-	2	2	4	2
HU	9	5	4	-	1	8	9	-	-	-	3	4	1	1
LV	11	7	4	-	7	4	6	4	1	-	6	1	4	-
RO	10	3	7	-	2	8	5	4	-	1	8	2	-	-
SE	11	6	5	4	1	6	-	11	-	-	8	3	-	-
UK	14	8	6	7	1	6	-	14	-	-	5	4	2*	3**

Notes: UK: \*The ILO definition of employment is used, denoting that some part of paid employment was being undertaken at the time of the interview. However, substantial underemployment was apparent, with some participants working as little as one hour a week. \*\*Refers to people who have retired from the labour market as a consequence of age or long-term ill health.

Source: FRA, 2011

Table A2: Sample composition – people with mental health problems

Country	Total no. of interviews	Men	Women	Living arrangement			Education			Employment			
				Alone (with partner)	Protected/ Group home	Family or friends	Compulsory/elementary	Secondary/ High school	University	Unemployed	Supported/protected	Open labour market	Other
<b>TOTAL</b>	<b>115</b>	<b>54</b>	<b>61</b>	<b>40</b>	<b>12</b>	<b>63</b>	<b>31</b>	<b>50</b>	<b>34</b>	<b>63</b>	<b>14</b>	<b>26</b>	<b>12</b>
BG	10	5	5	-	-	10*	-	5	5	4	5	1	-
DE	12	8	4	9	-	3	9	1	2**	4	4	4	-
EL	15	8	7	1	6	8	6	3	6	9	1	4	1
FR	16	7	9	10	-	6	-	11	5	2	-	5	9
HU	8	2	6	2	2	4	5	3	-	5	-	3	-
LV	12	6	6	2	3	7	3	4	5	6	1	4	1
RO	21	7	14	5	-	16	6	14	1	20***	-	1	-
SE	9	6	3	5	-	4	2	3	4	5	3	1	-
UK	12	5	7	6	1	5	-	6	6	8	-	3	1

Notes: BG: \*Two of the participants live as a family, but together with the man's mother and sister. DE: \*\*Not completed yet. RO: \*\*\*15 (six men and nine women) out of 20 unemployed participants attended a day care centre. Occasionally they received a small amount of 'pocket' money for the work performed there.

Source: FRA, 2011





## Annex 2: Methodology

The report is based on fieldwork interview based research in nine EU Member States: Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom. Additional background material produced through desk research covering all EU Member States allowed the contextualisation of the fieldwork findings.

The FRA administered the project and applied its own rigorous quality control measures including a review by its Scientific Committee. A large part of the background research and the fieldwork was outsourced to the Human European Consultancy, which formed a core research team composed of Neil Crowther, Edurne Garcia Iriarte, the National Institute for Intellectual Disability (Dublin), Anna Lawson (Leeds University), Oliver Lewis and Jasna Russo (Mental Disability Advocacy Centre), Rachel Stevens (NUI Galway) and Rannveig Traustadottir (University of Iceland). In addition, background studies and fieldwork research at the national level were conducted by national researchers; see Annex 3 for a full list. The research was supported by an ad hoc advisory board composed of the following civil society organisations: European Network of Independent Living (ENIL), the European Disability Forum (EDF), the European Network of (ex) Users and Survivors of Psychiatry (ENUSP), the European Platform of Self Advocates, and Inclusion Europe. In addition, the following experts kindly contributed to the work Michael Bach (Canadian Association for Community Living), Mark Priestly (Leeds University), Gerard Quinn (NUI Galway), and Lisa Waddington (Maastricht University). The responsibility for the analysis and conclusion lies with the FRA.



*“This is my house – well, actually it is a flat. I want to show that I live independently. Although I get support I’m an associate (of the support organisation) now, which means that I’m quite independent. I’ve been living here a long time.”*

*(United Kingdom respondent)*

### Primary data collection

Empirical research was carried out in nine EU countries (Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the United Kingdom) between November 2010 and July 2011. This was qualitative research underpinned by principles of participatory research methodology – a methodology which aims to empower the subjects of the social inquiry. It consisted of one-to-one semi-structured interviews and focus group discussions which will be outlined below.

### Participatory approach

Participatory research principles guided the development of the research design.<sup>128</sup> The methodology selected aimed to ensure that people with mental health problems and people with intellectual disabilities would be active participants at all stages of the study and that they and their representative organisations would be given a guiding role in the process of analysis and conclusion formulation.

Accordingly, the leading EU level NGOs representing people with mental health problems and people with intellectual disabilities, as well as other organisations working in the field of disability rights and independent living more generally, nominated members to take part on the project’s Advisory Board.

<sup>128</sup> For more information and references on emancipatory research see National Disability Authority (Ireland) proceedings from its 2005 conference on using emancipatory methodologies in disability research, available at [www.nda.ie/cntmgmtnew.nsf/0/87418679FAE58BoE80256Fo2004753E9?OpenDocument](http://www.nda.ie/cntmgmtnew.nsf/0/87418679FAE58BoE80256Fo2004753E9?OpenDocument).



*“Where I work we have a co-worker model. That means that we work equally with other people: a person with a learning disability and a person without a learning disability. That’s very important – it’s much better.”*

*(United Kingdom respondent)*

## Training

A two-day training event on the project methodology was held in October 2010. Principal researchers from the nine countries in which the empirical work was conducted were asked to attend. This event explored the underlying values and aims of participatory research as well as covering methods and matters relating to ethics, data protection and health and safety.

## People with mental health problems and people with intellectual disabilities

In order to respect the fact that there may be potentially important differences between the experiences of people with mental health problems and people with intellectual disabilities, the empirical research was conducted as two parallel and distinct strands.

## Interviewee samples

The sample of people with intellectual disabilities consisted of 105 people from the nine different countries. A detailed breakdown of the characteristics of this sample is to be found in Table A1 in Annex 1.

The sample of people with mental health problems consisted of 115 people, from the nine different countries. A detailed breakdown of the characteristics of this sample is to be found in Table A2 in Annex 1.

Neither sample included people falling into the following categories:

- people unable to communicate relatively easily in an interview situation;
- people currently living in obvious institutional regimes;
- people under guardianship whose guardian refused consent to the interview; and



*"Being loved by someone gives me a reason to live when I am in my darkest depression."*

*(United Kingdom respondent)*

- people under the age of 18 (although the adult participants were asked about childhood experiences).

## Methods

A range of research methods were used, comprising the following methods.

### ■ *One-to-one semi-structured interviews*

One-to-one semi-structured interviews with 220 people (115 people with mental health problems and 105 people with intellectual disabilities).

Interviewees were recruited by country researchers on the basis of purposive sampling. Assistance with recruitment was often provided by local and national NGOs working in areas connected with the human rights of people with mental health problems and people with intellectual disabilities.

### ■ *Focus groups with interviewees*

At least one focus group for interviewees with mental health problems and one for interviewees with intellectual disabilities was held in each of the nine countries.<sup>129</sup> Their purpose was to present the interviewees with the emerging findings and obtain their views and insights which were then fed into the analysis.

### ■ *Focus groups with stakeholders*

One focus group for stakeholders with expertise and experience relating to people with mental health

<sup>129</sup> In Germany, people other than the interviewees and their support persons were also present at these focus groups.



*"I like to go to rock concerts and to the cheering section of my favourite Swedish football team."*

*(Swedish respondent)*



problems and one focus group for stakeholders with expertise and experience relating to intellectual disability was held in each of the nine countries. Their purpose was to present stakeholders with the emerging findings and analysis and to seek their observations and insights on the situation in the country more generally. Stakeholders were representatives of organisations or bodies with an interest in the topics of this study. The organisations represented varied from country to country but wherever possible included a representative of a user-led organisation or group, representatives of government departments, representatives of ombudsman offices or national human rights institutions and representatives of professional bodies working in the field (e.g. psychiatrists and social workers).

#### ■ Peer review meeting

A two-day meeting with the participation of disabled persons organisations and groups representing people with mental health problems and people with intellectual disabilities from the countries covered by the fieldwork. The aim of the meeting was to validate and prioritise the draft findings. The meeting took place in Vienna in November 2011.

#### ■ Photo-voice methodology

Further one-to-one discussions were conducted with 63 of the original respondents (36 (excluding France) of whom had mental health problems, and 27 (excluding France and Greece) of whom had intellectual disabilities) based on photographs taken after the first interview by the person in question of images which they regarded as important to their lives. This technique, known as 'photo-voice', is a method which involves providing the



*"I feel safe using this technical aid so that I don't forget to turn off the cooker and the coffee-maker."*

(Swedish respondent)

research participants with a camera, asking them to take photographs and then explain the stories behind the images.<sup>130</sup> Photo-voice is generally regarded as an empowering method because it provides people with the power to decide which aspects of their lives they choose to document and which stories they choose to tell.

<sup>130</sup> For further information, see Nind, M. (2008) *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*, National Centre for Research Methods, available at <http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf>; - also Aldridge, J. (2007) 'Picture this: the use of participatory photographic research methods with people with learning disabilities', *Disability & Society*, 22(1), pp. 1-17.



*"Living in a 'normal' community and the importance of independent mobility."*

(German respondent)



*"This is the room at the community-based centre where I attend group sessions."*

(Bulgarian respondent)



*Other important aspects of everyday life documented by one of the respondents related to daily activities and to letting other people know more about it: 'Come and have a look!'*

(Swedish respondent)



After their interview, participants who were willing to take part in the photo-voice methodology were given a disposable camera and asked to take photographs of people, places, objects and whatever else they regarded as relevant to their lives and the issues discussed in the interview. When the photographs had been taken, the participant met the country researcher again and explained the meanings of the photographs. The information gathered from these discussions enriched the data already gathered from relevant participants in the initial interview.

The primary purpose of using photo-voice was to enable participants to use photographs they had taken to deepen their communication with the researcher, to provide a focus for additional discussion about aspects of their lives and, thereby, to enrich interview data. The photographs communicate relevant aspects of participants' lived experience, and with the permission of relevant participants, some have been included in this report.

## Secondary data collection

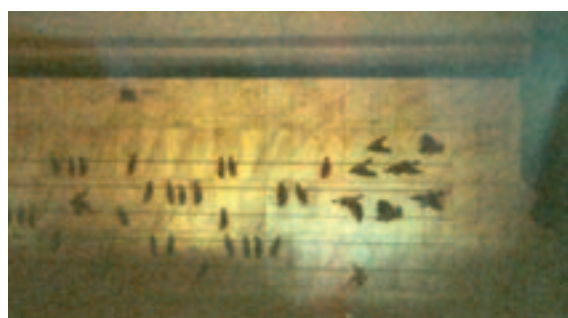
Secondary data and contextual information on community living, institutional living, legal capacity and access to justice was provided through desk research covering all EU Member States between October 2010 and October 2011. The desk research examines legal and policy developments, as well as examples of good practice drawing on government and non-governmental sources, such as academic research, NGO reports and other literature and publicly available information. The accuracy of the data and information provided was assessed by national authorities.

Desk research was also carried out between January 2011 and May 2011 on EU and international level developments. The findings are integrated in the present report and other relevant FRA reports.



*"It is a picture of the faceless crowd, which, stands behind the same banner and this unites them. He is just one of them, fighting for a society with solidarity and against injustice. "Like we step on ants, this is how they step on us". "I try to achieve balances. I want neither revolutionary dividing lines nor being apathetic."*

*(Greek respondent)*



*"The flight of birds means freedom to him. They open their wings and fly and their only danger are the stronger birds and men. At the same time this picture means condescension. This is what he feels when he sees birds sitting on wires."*

*(Greek respondent)*



*This nice scenery makes him feel "special [...] for living twice, after attempts of suicide, a divine fortune tells me that I am special, at least that it was not time for me to leave this world yet".*

*(Greek respondent)*



*"It's really important to have information that's accessible. We help people make things accessible."*

*(United Kingdom respondent)*



# Annex 3: External research team members

## Core research team

Neil Crowther, Independent expert, United Kingdom (from 15 November 2011)  
 Edurne Garcia Iriarte, National Institute for Intellectual Disability, Dublin, Ireland  
 Anna Lawson, Leeds University, United Kingdom  
 Oliver Lewis, Mental Disability Advocacy Center, Budapest, Hungary

Jasna Russo, Mental Disability Advocacy Center, Budapest, Hungary  
 Rachel Stevens, National University Ireland (NUI) – Galway, Ireland  
 Rannveig Traustadottir, University of Iceland, Iceland

## Country researchers

EU Member State	Name	Organisation
Austria	Tobias Buchner	<i>Lebenshilfe</i>
Belgium	Geert van Hove	Vrije Universiteit Brussels
Bulgaria	Slavka Kukova	Bulgarian Helsinki Committee
Cyprus	Simoni Symeonidou	University of Cyprus
Czech Republic	Jan Siska	Charles University, Faculty of Education
Denmark	Steen Bengtsson	Danish National Institute of Social Research
Estonia	Eve Pilt	Estonian Patients Advocacy Association
Finland	Antti Teittinen	Finnish association on intellectual and developmental disabilities
France	Dominique Velche	Centre Technique National d'Études et de Recherches sur les Handicaps et les inadaptations (CTNERHI)
Germany	Petra Gromann	University of Fulda, Institut personenzentrierte Hilfen
Greece	Maria Mousmouti	Centre for European Constitutional Law
Hungary	Tamas Gyulavári	Eötvös Loránd University (ELTE), Labour Law Department, Budapest
Ireland	Rachel Stevens	National University of Ireland (NUI) – Galway
Italy	Maura Benedetti	University of Rome, Faculty of Psychology
Latvia	Ieva Leimane-Veldmeijere	Resource Centre for People with Mental Disability “ZELDA”
Lithuania	Dovile Juodkaite	Global Initiative on Psychiatry, Vilnius Office
Luxembourg	Arthur Limbach-Reich	University of Luxemburg
Malta	Anne-Marie Callus	Kummissjoni Nazzjonali, Persuni b'Dizabilita
Netherlands	Anna vd Zwan	Stichting Perspectief
Poland	Ewa Wapiennik	Academy of Special Education
Portugal	Sandra Marques	Federação Nacional de Cooperativas de Solidariedade Social (FENACERCI)
Romania	Georgiana Pascu	Centre for Legal Resources
Slovakia	Maros Matiasko and Zuzana Durajova	
Slovenia	Darja Zavirsek	University of Ljubljana, School of Social Work
Spain	Agustin Huete	InterSocial
Sweden	Rafael Lindqvist	University of Gothenburg
United Kingdom	Sarah Woodin	University of Leeds

## Consortium management

Human European Consultancy – Piet Leunis and Andrea Trotter  
Mental Disability Advocacy Center – Oliver Lewis  
Centre for Disability Studies, University of Leeds – Mark Priestley  
Centre for Disability Law and Policy, National University of Ireland (NUI) – Galway – Gerard Quinn

## Advisory board

### European NGOs:

European Network of Independent Living – represented by John Evans  
European Disability Forum – represented by Javier Guemes  
European Network of (ex) Users and Survivors of Psychiatry – represented by Debra Shulkes  
European Platform of Self Advocates – represented by Senada Halilcevic  
Inclusion Europe – represented by Geert Freyhoff

### Scientific members:

Michael Bach, Canadian Association for Community Living  
Mark Priestly, Leeds University  
Gerard Quinn, NUI Galway  
Lisa Waddington, Maastricht University









European Union Agency for Fundamental Rights

**Choice and control: the right to independent living**

Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States

2013 — 82 p. — 21 x 29.7 cm

ISBN 978-92-9192-952-8

doi:10.2811/88538

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These three FRA reports provide a legal analysis of issues relating to the rights of persons with mental health problems and persons with intellectual disabilities.



## HELPING TO MAKE FUNDAMENTAL RIGHTS A REALITY FOR EVERYONE IN THE EUROPEAN UNION

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities establishes the right to live independently and be included in the community. Drawing on the findings of interview-based research with persons with mental health problems and persons with intellectual disabilities, this report examines how they experience the principles of autonomy, inclusion and participation in their day-to-day lives. The results show that although much has been done, more efforts are needed to ensure that persons with mental health problems and persons with intellectual disabilities have more choice and control over their lives and are included in the community on an equal basis with others. Most efforts to date have focused on deinstitutionalisation, but to achieve true independent living they should be accompanied by a range of social policy reforms in the areas of education, healthcare, employment, culture and support services. Key initiatives in policy, law and practice, identified in this report, can facilitate progress towards realising the right to independent living of persons with disabilities throughout the European Union.



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Publications Office

ISBN 978-92-9192-952-8



9 789291 929528