

EQUALITY



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

SUMMARY REPORT



FRA

EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS



This report addresses matters related to 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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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 (UN) 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 they 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 summary 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 summary 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 the areas of education, healthcare, employment, culture and, not least, support services. Only then will the rights enshrined in the CRPD become 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. It also provides some evidence on which to base such a discussion. The research brings to light the situation of persons with mental health problems and persons with intellectual disabilities – 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.

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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 is a chance which most of humanity takes for granted. The importance of this chance is recognised by the 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 summary 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 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.¹ 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. 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 that those with such disabilities face in everyday life across several EU countries.

¹ The fieldwork was carried out for FRA by country researchers in each of the nine Member States covered by the project: Slavka Kukova (Bulgaria), Dominique Velche (France), Petra Gromann (Germany), Maria Mousmouti (Greece), Tamas Gyulavári (Hungary), Ieva Leimane-Veldmeijere (Latvia), Georgiana Pascu (Romania), Rafael Lindqvist (Sweden) and Sarah Woodin (United Kingdom). For more detailed information on the methodology and research consortium for the FRA project *The fundamental rights of persons with mental health problems and persons with intellectual disabilities*, including an analysis of methodological challenges and limitations, see full report FRA (2012) *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*, Luxembourg, Publications Office of the European Union.

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 is a consistent theme of this research; it remains, however, far from realisation. Respondents describe their lives as restricted by a general lack of power and opportunity; they say, nevertheless, that as power and opportunity are gradually transferred to them they undergo a form of liberation. Many of them are caught between these two states.

"I want my own key and my own front door." (Man, Latvia, 34)

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.

"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 institution one cannot find anything." (Woman, 44, Bulgaria)

"When you live in the hospital, they watch where you are going, what you are doing. I really hate that. There is a difference between a group home and a hospital. And in the morning you can sleep in. You do not have to

get up. When you have to go to work you have to control what time you get up. But on, say, holidays, you can sleep all you want [...]."

(Man, 31, Latvia)

"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 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."

(Man, 45, Sweden)

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.

"First of all, I don't like special school. It's not a good solution. To separate people just because you happen to have a diagnosis is not right. [...]"

(Man, 45, Sweden)

"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."

(Man, 32, 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 at the day care centre. With people in the outside world." (Woman, 52, Greece)

"Well, I help in the winter [...] clearing snow [...]. So I work for people and they pay me either in cash or with some food. [...] They are happy to have me because they know I do a very good job, when they need it I do it, and

when they need the job done next time they give it to me every time [...] to do some gardening, weed the potato patch.” (Man, 30, Latvia)

“What I want is the dream of every person; to find a job at some point. I tell my father ‘Please, think what kind of job I could do’ and he tells me ‘I will think about it’. Because he has not, I thought on my own and I told him that I want to work at the new supermarket. But they do not let me.” (Woman, 31, Greece)

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.

“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)

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.

“I stopped [the help from the educators who assisted me in managing my budget, to organise my home and to file my papers] because I felt autonomous [...] I could make do on my own [...] so I said to myself that, now, I can take care of myself.” (Woman, France)

“This personal budget enables me to build my life up all over again.”

(Woman, 49, Germany)

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.

“I don’t know about human rights but I’d like the government to listen to us.”

(Woman, 38, United Kingdom)

“We will show society that we are capable too. We can do more than people believe. We need to come out!” (Woman, 53, Sweden)

“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)

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.

“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)

“Because 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)

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.

“It may also happen that you need to make a new application for support, 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)

“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.” (51-year old man, United Kingdom)

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.

“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)

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.

“I was very much bullied in school [...] in [high school] ...I pinched money from my mother so that I could buy myself friends. That was the only way to get friends. I was tough.” (Man, 31, Sweden)

“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)

“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)

“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)

“We choose what program to watch, we like several movies and programs. We all have own clothes and the social workers come with us when we need to buy clothes and other things. 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 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.

“Please, do not tell anyone 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)

“A lot of peer support organisations 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)

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.

“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)

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. They were also concerned about the impact it would have on their ability to live independently in the long term.

“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)

“I am currently living with my mother. I am very pleased with the life I am leading. I would like to get married.” (Woman, 46, Greece)

“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)

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.

“What I am detecting is a degree of intellectual frustration because mental health service user] 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.”
(Woman, 55, 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 justify 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 did not inform them in the first place. What could I say?” (Man, 40, Greece)

“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)

“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)

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.

“I’ve got a wonderful clinic, I can turn up straight away in a crisis and I feel very comfortable there.” (Woman, 50, Germany)

“Because psychiatric patients do not have problems with their body but with their mind, they definitely need to be treated well, like human beings. Everybody needs to be treated like human beings without any exceptions.” (Woman, 36, Hungary)

“At the moment I have an excellent GP who is psychotherapy GP trained so he’s a real diamond.” (Woman, 55, United Kingdom)

“My family doctor did not take me seriously when I talked about my physical complaints.” (Man, 42, Sweden)

“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 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)

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.

“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)

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.

“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)

“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)

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.

“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)

“My ‘dad’ influences me in many things, he supports me financially, and due to that 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)

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.

“When they started searching my things I cried, because I felt like a prisoner. It was deeply humiliating. I could not stop crying, and then they put me in ward 1, a closed-type ward, where you are not allowed to go out and there was just a bed and strange people, who really did talk and behave in a strange way. I lay down and cried again. I could not understand what to do.” (Woman, 40, Latvia)

“Dark rooms, very small spaces, always a stale and foul odour, bed sheets were dirty, there was no place to take a bath, and toilet bowls were cracked.” (Woman, 39, Romania)

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.

“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)

“I really, really keep my mental health problem as a secret, as a huge secret.” (Woman, 33, Hungary)

“With the illness it was like this: I was practically excluded from the family.” (Woman, 52, Germany)

“When I show him the disability card, he starts yelling so the whole bus can hear him: ‘The invalids are here, again those invalids!’”
(Woman, 25, Latvia)

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 risk holding back progress towards meaningful independent living.

“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)

“I feel well the way I am now. I cannot imagine coping with life if I lived in another flat and alone. I had a friend who committed suicide because he only had butter and bread in his fridge and did not have any income.”

(Woman, 51, Bulgaria)

“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)

Conclusions

The findings demonstrate that many of the participants in this research had often reduced opportunities to live independently and participate in community life. The results also illustrate the positive impact reform processes are 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 summary 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 that 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 summary 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. They also reflected on the inclusion and participation in community life that opened up to them.

Individuals striving to live independently in the community need an enabling community context. The research findings 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, in turn, 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 that 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 for persons with disabilities. They 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. Moreover, it 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.”²

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. In its *Concluding observations on Spain*, the committee recommended that the State Party “reviews its laws that allow for

² United Nations Committee on the Rights of Persons with Disabilities (2011) *Concluding observations of the Committee on the Rights of Persons with Disabilities – Spain*, Sixth session, 19–23 September 2011, para. 34.

the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; repeal provisions that authorize involuntary internment linked 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.”³

- **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.**

³ *ibid.*, para. 36.

Without financial independence autonomy and choice cannot be achieved. Therefore, appropriate employment, sufficient income support and benefits and other relevant measures are necessary as precondition 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.⁴

- **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 2000/78/EC 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; the enforcement, however, 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 2000/43/EC.

- **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

⁴ *Ibid.*, para.9 and 39-42.

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.”⁵

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 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. EU 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 in which 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.**

⁵ *ibid.*, para. 39.

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. Measures are also needed to safeguard the existence and functioning of such organisations, 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 both Article 29 of the CRPD and the view of the Committee on the Rights of Persons with Disabilities, stating 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".⁶ 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.

⁶ *Ibid.*, para. 48.

- **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.

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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