



EUROPEAN POLICY BRIEF



ACTIVE CITIZENSHIP IN THE LIGHT OF NEW SOCIAL
INEQUALITIES

CHANGE AND CURRENT STATUS IN THE LIFE COURSE
OF PERSONS WITH PSYCHO-SOCIAL DISABILITIES

September 2014

INTRODUCTION

Twenty-five per cent of the EU population experience a significant episode of mental illness during his or her lifetime. Persons included in this group are diverse and face different mental health issues, from depression to addictions, schizophrenia or eating disorder. The financial cost of mental health has been calculated between 3 and 4 per cent of the EU GDP. In addition, persons with psychosocial disabilities still have a higher probability of being unemployed, have a poor economic situation and live in social isolation.

According to the UN Convention on the Rights of Persons with Disabilities (UN CRPD), services should be provided in the community, should be person-centred and involve closely individuals in decisions. The UN CRPD identifies assistance and social services as means for autonomy and participation. The UN CRPD has been signed and ratified by all the nine countries covered by the DISCIT project. Nonetheless, despite policy adherence to its principles, existing policies have not been reviewed in light of the CRPD and fail to ensure active citizenship for persons with psychosocial disabilities.

Despite the process of deinstitutionalisation that started in the 60's in order to allow persons with disabilities to live in the community, institutional settings continue to be developed. Furthermore the community-based services are insufficient and do not always meet the needs of persons with psychosocial disabilities, preventing them from enjoying active citizenship.

Therefore, in order to address this issue, understanding the role of the welfare system in promoting or hindering protective factors and active citizenship is crucial.

EVIDENCE AND ANALYSIS

Different concepts of mental health, the need or lack of a medical diagnosis have an impact on the development of policies addressing citizenship and participation.

One of the main conclusions from the literature review is that the framework of the universal disability model is the most adequate to grasp and address challenges faced by persons with psychosocial disabilities. This model goes beyond and encompasses both the medical and social models. Through the universal disability model, disability and mental health are viewed from a dynamic point of view, by considering the individual's life evolution but also the influence of the environment, through the evolution of the socio-economic structures as well as the fact that mental health issues can affect everyone at any time in life and may also evolve over time.

Many people with mental health problems still live in institutions or remain for long periods in hospital settings without adequate alternatives. Yet, studies have found improvements in the quality of life and personal development of people who move out of institutions into community living. Still, improvements have to be made in this area, as services are often scattered and fail to meet individual needs. In addition, bureaucratic procedures, lack of available care and services choice for users, unclear accountability mechanisms, complex arrangements and funding schemes, and increased conditionality, prevent persons with psychosocial disabilities to benefit from services.

Small-scale living arrangements offer persons with intellectual disabilities and mental health problems more friends, better access to generic services, more chances to improve skills, and greater satisfaction and well-being. Yet, community-based services often fail to provide opportunities for employment, or deliver meaningful adult activities, which imply a risk of poverty, insecurity and isolation. There is lack of cooperation among different actors of institutional assistance and support suppliers acting in the various relevant areas such as housing, income support, health care, rehabilitation services, and social assistance.

Solutions identified by DISCIT include the joined-up health and social services delivered by multi-disciplinary community teams, and more generally one-stop-shop arrangements for these benefits and services. Such arrangement may improve the users' possibility of control over the provision of social services.

In parallel to an incomplete deinstitutionalisation process, we have seen in the last years the development of a decentralisation process and the introduction of New Public Management, leading to a "marketization" of care, meaning that different welfare provisions are delivered by a variety of public and private suppliers.

This has also limited the involvement of persons with psychosocial disabilities, preventing them from exercising their influence in designing and planning the services that better meet their needs. Users of services could be involved in a variety of areas such as complaints procedures, evaluation and feedback, management boards, and should first and foremost be allowed to make decisions for themselves.

Among good practices researched in terms of support for persons with mental health problems, we can find ‘Case management’. However, it is far from being available in all European countries. Sweden has developed a home-made model of case management called *Personliga Ombud* (i.e. personal agent) that help individuals make decisions by giving advice and information on managing everyday life, but also by breaking isolation and encouraging persons with psychosocial disabilities to participate in social activities.

DISCIT researchers also looked at the welfare provisions concerning mental health throughout their lifetime, starting from childhood and education. It is important to note in this framework that mental health issues can develop at various moments in life. Social provisions and social regulations can influence the protective and/or risk factors for the mental health of citizens. Governments play a crucial role in the prevention of psychosocial problems by creating good conditions for education, family life, and employment, and by preventing alcohol and drug abuse, and helping with debt and social isolation.

While some countries have fully developed an inclusive education system in line with the UN CRPD, other countries still organise “special education” alongside with mainstream education (Germany, Switzerland, the UK, Ireland, Serbia). Furthermore even within inclusive education systems, the needs of children with psychosocial disabilities are not sufficiently taken into account.

Persons at ‘working age’: 18-65 years-old, are entitled to social benefits and services, which usually include unemployment pensions, disability pensions, activation programmes and/or sheltered work. However, few services are specifically designed for persons with psychosocial disabilities. In addition, an increasing number of young persons with mental health issues are granted a disability benefit instead of receiving support in order to enter employment. Several countries have developed activation policies. This has led to unintended consequences such as limited access to benefits, putting focus on the individual’s work motivation and performance rather than improving opportunities for participation, and consequently achieving limited results. The Individual Placement and Support model is more in line with the active citizenship model, since it takes into account the person’s wishes and preferences, achieving an increase in self-esteem and quality of life.

Finally, people over 65 do not benefit from services that are designed to address mental health issues, despite the fact that they affect at least 15% of the population. Moreover, institutional settings still prevail in many countries.

Stigma is still a reality for persons with psychosocial disabilities. The logic of confinement of persons with psychosocial disabilities still prevails. Therefore, education programmes targeting general society are necessary, alongside anti-discrimination legislation.

Accessibility is also a key element of autonomy and security. If education, employment and services are not accessible, participation by citizens is impossible. The main problem in the area relates to the gap between the legislation and its implementation. A whole culture of accessibility must be developed.

Through this analysis, we can distinguish between measures of “care” and measures of “active citizenship”. In many countries we still see a prevalence of ‘care’ measures while good practices such as supported employment, personalised support, personal agents, and personal assistance models of recovery-oriented that have a potential to facilitate Active Citizenship are still limited.

POLICY IMPLICATIONS AND RECOMMENDATIONS

- The paradigm shift developed in policy discourse as a result of the CRPD, must be translated into the development of new strategies and policies. Previous disability policy models have simply been adapted without being profoundly revised as to ensure security, autonomy and influence.
- Comparable data must be developed on the results of policies directed at persons with psychosocial disabilities.
- More personalised services, such as the personal agent actor, must be developed.
- Programmes must involve processes of coordination between various levels in a multi-level governance system, and collaboration between various organisations on the local level.
- Mental health care must be developed to address the whole life spectrum and allow for recovery. The impact of socio-economic structure must be addressed as to prevent the development of mental health issues.
- Persons with psychosocial disabilities must be involved in the development of services they benefit from, ranging from education to housing, employment, healthcare.
- Participation and independent living must be at the core of all policies addressing persons with disabilities whether in education, housing or employment. There must be a complete shift from institutions.
- Develop education programmes to fight stigma.
- Reinforce non-discrimination legislation at national and European level.
- Ensure implementation of accessibility legislation and develop universal design.
- The mental health dimension must be considered in all policies.

RESEARCH PARAMETERS

Once submitted the state-of-the-art on the social services and the deinstitutionalisation process for persons with psychosocial disabilities reported in the deliverable “Diversity and change of the life courses of persons with psycho-social disabilities – the impact of services. Literature review”, DISCIT researchers gained original knowledge from life-course interviews to this target group in the nine countries involved in DISCIT (Germany, Italy, Sweden, Norway, UK, Ireland, Switzerland, Czech Republic and Serbia). This group of countries represents the four welfare regimes that frame the DISCIT approach to analysing active citizenship: conservative regime, liberal, social-democratic, and post-communist.

Apart from information and data, the nine research teams conducted interviews with men and women with psychosocial disabilities born around 1950, 1970 and 1990. The goal of these interviews was to obtain knowledge on the changes of the services available to them throughout their lifetime. The topics discussed included, among others, social services, education, employment, new technologies, and participation in the society.

PROJECT IDENTITY

PROJECT NAME Making Persons with Disabilities Full Citizens - New Knowledge for an Inclusive and Sustainable European Social Model (DISCIT)

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Mental Disability Rights Initiative of Serbia - MDRI-S
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National University of Ireland - NUI Galway - Centre for Disability Law and Policy
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Swiss Paraplegic Research - SPF - Disability Policy Unit
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University of Cologne - UCO - International Research Unit Disability Studies
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FURTHER READING *Working Paper 'Diversity and change of the life courses of persons with
psycho-social disabilities - the impact of social services', January 2014*

*Working Paper 'Change and current status in the life course of persons
with psycho-social disabilities - findings based on life course
interviews', available November 2014*