

SELF-ADVOCACY OF PERSONS WITH DISABILITIES IN THE REPUBLIC OF MOLDOVA FROM THE PERSPECTIVE OF INTERNATIONAL HUMAN RIGHTS STANDARDS

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Rezumat

Articolul explorează conceptul de autoreprezentare a persoanelor cu dizabilități și importanța acestuia în contextul standardelor internaționale privind drepturile omului. Sunt examinate, de asemenea, legislația și politicile Republicii Moldova pentru a reflecta modul în care acestea asigură premise pentru autoreprezentarea persoanelor cu dizabilități. Procesul de aderare la Uniunea Europeană, demarat recent de Republica Moldova, influențează agenda țării privind drepturile persoanelor cu dizabilități. În acest sens, articolul oferă o perspectivă privind standardele și prevederile legale ale Uniunii Europene cu impact asupra autoreprezentării persoanelor cu dizabilități. În realizarea articolului a fost aplicată metoda analizei documentare, fiind analizate publicațiile științifice relevante domeniului, dar și cadrul juridic național și internațional în materie de drepturi ale persoanelor cu dizabilități. Se constată astfel că legislația moldovenească respectă standardele internaționale privind drepturile persoanelor cu dizabilități, oferind un fundament legal solid pentru autoreprezentarea acestora. Totuși, succesul autoreprezentării depinde de nivelul de implicare al persoanelor cu dizabilități în promovarea propriilor interese și de accesibilitatea mediilor și informațiilor asigurate de factorii de decizie pentru a facilita participarea lor efectivă.

Cuvinte cheie: persoane cu dizabilități, autoreprezentare, drepturile omului, politici incluzive.

Summary

The article delves into the concept of self-advocacy among persons with disabilities and its significance within the framework of international human rights standards. It analyses the legislation and policies of the Republic of Moldova to demonstrate how they establish conditions for the self-advocacy of persons with disabilities. The recently initiated process of accession to the European Union by the Republic of Moldova has implications for the country's approach to the rights of persons with disabilities. Consequently, the article also offers insights into the standards and legal provisions of the European Union that affect the self-advocacy of persons with disabilities. The article employs the method of documentary

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analysis to investigate relevant scientific publications and to scrutinize the legal frameworks at both the national and international levels that are relevant to the rights of persons with disabilities, enabling their self-advocacy and participation. The article concludes that Moldovan legislation is aligned with international standards on the rights of persons with disabilities, providing a robust legal basis for their self-advocacy. However, the effectiveness of self-advocacy depends on how actively involved persons with disabilities are in promoting their own interests. Additionally, it depends on whether decision-makers make media and information easily accessible to them, thus enabling their full and meaningful participation.

Keywords: persons with disabilities, self-advocacy, human rights, inclusive policies.

Résumé

L'article explore le concept d'autoreprésentation des personnes en situation de handicap et son importance dans le contexte des normes internationales en matière de droits de l'homme. Il examine également la législation et les politiques de la République de Moldavie pour déterminer dans quelle mesure elles favorisent l'autoreprésentation des personnes en situation de handicap. Le processus d'adhésion à l'Union européenne, récemment entrepris par la République de Moldavie, influence l'agenda du pays en matière de droits des personnes en situation de handicap. Dans cette perspective, l'article présente un aperçu des normes et des dispositions juridiques de l'Union européenne ayant un impact sur l'autoreprésentation des personnes en situation de handicap. Pour rédiger cet article, la méthode de l'analyse documentaire a été utilisée, consistant en l'examen des publications scientifiques pertinentes dans le domaine ainsi que du cadre juridique national et international concernant les droits des personnes en situation de handicap. Il ressort que la législation moldave respecte les normes internationales en matière de droits des personnes en situation de handicap, offrant ainsi une base légale solide pour leur autoreprésentation. Cependant, le succès de cette autoreprésentation dépend du degré d'engagement des personnes en situation de handicap dans la promotion de leurs propres intérêts et de l'accessibilité des médias et des informations assurées par les décideurs pour faciliter leur participation effective.

Mots-clés : personnes en situation de handicap, autoreprésentation, droits de l'homme, politiques inclusives.

1. Foreword

Since emerging as a prominent academic theme in the 1980s, the self-advocacy of people with disabilities has experienced remarkable growth, becoming an important research topic both internationally and nationally. Several key factors have contributed to this significant surge in interest. Firstly, *changes in the perception of disability* have been notable. There has been a gradual paradigm shift in how society views disability, moving away from a traditional perspective focused on limitations and deficiencies towards a more inclusive outlook that recognizes functional diversity and values the significant contributions of people with disabilities to society.

Secondly, *advancements in human rights* have bolstered self-advocacy by promoting principles of non-discrimination, inclusion, and full participation of people with disabilities in all aspects of life. The ongoing development of the

human rights legal framework has provided a solid basis for increasing the visibility and voice of people with disabilities in decision-making processes and society at large.

Additionally, the everyday *challenges faced by people with disabilities* have underscored the necessity of self-advocacy as an effective tool for amplifying their voices and addressing the specific difficulties they encounter. Self-advocacy provides an essential platform for highlighting and addressing these issues, contributing to the construction of a more inclusive and equitable society.

In the context of the Republic of Moldova, where the concept of self-advocacy is in its early stages, it is important to develop and support initiatives that promote the active involvement of people with disabilities in self-advocacy and advocacy processes to ensure that their needs and rights are understood and addressed appropriately. Analysing the legal framework represents a crucial first step in this regard. It is important to assess whether national legislation provides the necessary premises for self-advocacy in accordance with international human rights standards. This analysis could identify gaps in existing legislation and provide guidance for improving or developing new laws or policies that better support the self-advocacy of people with disabilities.

2. Conceptual Approaches of Self-Advocacy of Persons with Disabilities

Throughout history, persons with disabilities often faced significant barriers to self-expression and were frequently excluded from decision-making processes, leaving them voiceless. Self-advocacy is essential for participation of persons with disabilities in social, political, cultural, economic, and other aspects of life, requiring the ability to articulate and advocate for their own needs and desires in various situations. When individuals do not represent their own interests or express their opinions and preferences, several negative consequences may arise; they may feel misunderstood or undervalued, be compelled to act against their values or what they perceive as right for themselves, develop a negative self-image, undermine their confidence in their abilities and decisions, lack control over their lives, among others.

In the realm of disability studies, self-advocacy is primarily discussed in relation to intellectual or learning disabilities (Callus, 2013), (Gray and Jackson, 2002), (Goodley, 2004), reflecting the complexities therein. Individuals with intellectual disabilities may face challenges understanding their identity and self-perception, hindering precise expression of thoughts and emotions. They encounter higher degrees of discrimination and stigma, often experiencing more severe marginalisation than other disability types. Some individuals with intellectual disabilities may find it challenging to communicate verbally, impeding effective expression of their ideas, needs, and preferences.

There are various definitions of „self-advocacy” covering multiple facets: from self-determination to influencing public policies in the disability field, from

identifying one's own needs to qualitative changes in a person's life, and more (Cojocaru, 2019).

Thus, some definitions focus on the individual experiences of persons with disabilities speaking for themselves, asserting their rights, making decisions, and taking responsibility for their actions and lives. Other definitions offer a perspective of collective action, where groups of persons with disabilities unite for social justice (Callus, 2013) (Gray and Jackson, 2002).

Rapley M. interprets self-advocacy through the lens of social roles (Rapley, 2004) by examining how individuals with disabilities navigate and assert themselves within societal structures and expectations. This perspective views self-advocacy not only as a means for individuals to express their own needs and interests but also as a way to challenge and redefine the roles traditionally assigned to them by society. It can be seen as the rejection of predefined social roles or stereotypes associated with disability. Instead, persons with disabilities adopt roles that better align with their own perception and understanding of themselves. This rejection is driven by the fact that people with disabilities do not exclusively identify with their disability, as it is influenced by various contexts and environments. In essence, it highlights how self-advocacy can empower individuals to actively shape their identities and roles within the social context, asserting their agency and advocating for their rights and inclusion.

Whitehead T.D. and Bernard J. define self-advocacy within the dynamics of social power. They analyse how persons with disabilities represent themselves within social relationships, where power often lies with others, and persons with disabilities are frequently negatively perceived by society (Whitehead and Bernard, 2004). Discriminatory policies and practices, such as forced institutionalisation or segregation, exemplify power over persons with disabilities. Despite recent positive changes like deinstitutionalization, power dynamics have not significantly shifted. Persons with disabilities often struggle with control over their choices and resources, and self-advocacy becomes a means to address this imbalance.

A common thread among these approaches is that self-advocacy empowers persons with disabilities to advocate for themselves and others in similar situations, amplifying their voices and experiences. It serves as a tool for defending and promoting their rights, encouraging active engagement in society (Goodley, 2004).

Given its fundamental role in respecting and advancing the rights of persons with disabilities, self-advocacy holds particular importance within international human rights standards. By fostering self-advocacy and ensuring access to effective participation mechanisms, countries can fulfil their international human rights commitments and promote the inclusion of persons with disabilities in society.

3. Legal Foundation for the Self-Advocacy of Persons with Disabilities in the Republic of Moldova

As of January 1, 2023, the number of individuals recognized as having disabilities in the Republic of Moldova was 162.3 thousand, representing 6.5% of the total resident population of the country (NBS 2023). The rights and interests of persons with disabilities in Moldova are represented by at least 60 civil society organisations, which are members of the Alliance of Organizations for Persons with Disabilities from the Republic of Moldova (AOPD 2024). In Moldova, there are no dedicated organizations for self-advocates with intellectual disabilities. However, since 2015, NGOs active in the field of disability rights have supported self-advocacy by establishing an informal national network of self-advocates, comprising approximately 150 individuals.

The right to self-advocacy is intertwined with the broader concept of freedom of speech, as it allows individuals to speak up for themselves and assert their opinions without fear of repression or censorship. The right to freedom of opinion and expression was initially acknowledged through the *Universal Declaration of Human Rights* (UDHR), adopted by the United Nations General Assembly in 1948. Article 19 of the UDHR stipulates that „everyone has the right to freedom of opinion and expression.” (UDHR 1948). This right underpins many others, such as assembly and the ability to participate in public affairs, etc. In 1990, the Republic of Moldova ratified the UDHR, committing to safeguard and promote the fundamental rights and freedoms of its citizens in line with the standards outlined in the UDHR (Law on UDHR ratification 1990).

The UDHR served as the cornerstone for various international human rights agreements. *The United Nations Convention on the Rights of Persons with Disabilities* (CRPD 2006) stands as a significant example in this regard, setting specific benchmarks for safeguarding and advancing the rights of persons with disabilities, as well as providing the groundwork for their self-advocacy. The CRPD was negotiated and drafted through a participatory process involving persons with disabilities themselves (Pineda and Catalano, 2024).

The preamble to the CRPD acknowledges „that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,” as enshrined in the Universal Declaration of Human Rights, and asserts that „persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them.” The principles of self-advocacy are enshrined in the CRPD's General Principles, particularly emphasizing the principle of „Full and effective participation and inclusion in society” (Article 3, c.). The CRPD's motto „Nothing About Us Without Us!” underscores the importance of inclusion, emphasizing that persons with disabilities should have a say in all matters concerning them. Participation provides a platform for self-advocacy. When persons with disabilities participate in public life, including voting, holding public service positions, engaging in policy discussions, etc. they could express their views and influence decisions that affect them.

Furthermore, the CRPD outlines the groundwork for self-advocacy within its General Obligations by advocating for close consultation and active involvement of persons with disabilities in the development and execution of legislation and policies to implement the CRPD, as well as in other decision-making processes pertaining to issues affecting persons with disabilities (Article 4 (3)). Simultaneously, Article 21 of the CRPD, „Freedom of expression and opinion and access to information” mandates all state parties to „take appropriate measures to ensure that persons with disabilities can exercise their right to freedom of expression and opinion [...] on an equal basis with others [...].”

The CRPD highlights the right of persons with disabilities to form their own organizations (article 29 (b, ii)). These organizations are seen as a way for persons with disabilities to collectively express their needs and interests. This collective action is a key aspect of self-advocacy. In addition, participation in these organizations can help persons with disabilities develop advocacy and negotiation skills, which empowers them to better represent themselves and their goals.

The CRPD was ratified by the Republic of Moldova in 2010 (Law on CRPD ratification 2010). The ratification process followed significant advocacy efforts by civil society, with prominent contributions from organizations active in the disability field and persons with disabilities themselves. Approximately 63 organizations and advocacy groups were actively involved in advancing the ratification process of the CRPD in the Republic of Moldova. Hence, civil society activism, inclusive of the utilization of self-advocacy mechanisms and advocacy by persons with disabilities, played a pivotal role in effecting substantial reforms in the realm of disability within the country (Munteanu, 2018).

An additional mechanism for enforcing and protecting the rights outlined in the CRPD is *The Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities* (Optional Protocol 2008). It is an international treaty that allows individuals or groups to file complaints with the Committee on the Rights of Persons with Disabilities (Committee) if they believe their rights under the CRPD have been violated. Self-advocacy skills are crucial for individuals to understand their rights and navigate the complaints process. Essentially, this Optional Protocol serves as a significant avenue for self-advocacy for persons with disabilities. The Optional Protocol also enables the Committee to investigate complaints and conduct inquiries into systematic violations of the rights enshrined in the CRPD. Persons with disabilities can use self-advocacy skills to provide information and participate in these investigations, ensuring their voices are heard. While the Optional Protocol doesn't directly focus on self-advocacy, it creates mechanisms that can be used by people with disabilities to advocate for themselves and hold governments accountable for upholding their rights.

In 2021, the Parliament of the Republic of Moldova ratified the Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities, affording them access to an international grievance mechanism in instances of rights violations (Lege ratifiable Protocol Optional 2021), and thus enhancing opportunities for self-advocacy.

The integration of international standards concerning the rights of persons with disabilities (as articulated in the CRPD) into national legal frameworks was effectuated through Law No. 60 of March 30, 2012, on Social Inclusion of Persons with Disabilities. The foundations for self-advocacy are embedded within the principles of law application (Article 5), encompassing aspects such as freedom of choice and autonomy, liberty to make independent decisions, and comprehensive and effective engagement in societal affairs. Adherence to these principles is obligatory for all rights enshrined in the legislation (Lege Incluziune Socială 2012).

To fulfil the provisions of the CRPD and of Law 60 on Social Inclusion of Persons with Disabilities, several policy documents have been developed and implemented. An important legislative achievement is the National Program for the Social Inclusion of Persons with Disabilities for the years 2024-2028 (draft), which includes a Specific Objective – 1.3. Expanding opportunities for all persons with disabilities to actively engage in social and political life over the next 5 years. Achieving this specific objective has important potential to contribute significantly to strengthening the self-advocacy of persons with disabilities in the Republic of Moldova because their involvement in social and political life provides them with the opportunity to express their opinions, experiences, and needs from a personal perspective.

This policy document was preceded by the National Program for the Social Inclusion of Persons with Disabilities for the years 2017-2022 (Program Incluziune Persoane cu Dizabilități 2017), whose intervention priorities were established as a result of consultations with various stakeholders, including persons with disabilities. This Program, in turn, was preceded by the Strategy for the Social Inclusion of Persons with Disabilities (2010-2013) (Program Incluziune Persoane cu Dizabilități 2010). However, at that stage, persons with disabilities were not directly involved in the drafting processes and public consultations, which was only possible through civil society organizations representing their interests. Therefore, it is noted that between the three policy documents, persons with disabilities have become more active and engaged in decision-making processes, demonstrating an increased level of civic participation, including through advocacy and self-advocacy.

The premises for self-advocacy of persons with disabilities are found in the Concluding Observations of the UN Committee on the Rights of Persons with Disabilities regarding the initial report of the Republic of Moldova on the implementation of the CRPD (Finally Observation ONU 2017). The UN Committee alerts to a low level of participation of persons with disabilities in political, social, cultural, etc., life and recommends that the state take action to provide opportunities for their participation. At the same time, the UN Committee's Observations serve as a basis for advocacy actions among persons with disabilities.

At the end of 2023, the Republic of Moldova initiated the process of accession to the European Union (the EU), which entails aligning national legal frameworks with the EU standards. The EU social inclusion policies provide premises for self-advocacy. *The European Commission's Strategy for the Rights of*

Persons with Disabilities 2021-2030 (European Commission 2021), adopted in 2021, aims to progress towards ensuring that all persons with disabilities in Europe [...], enjoy their rights, have equal opportunities to participate in society and the economy, [...] regardless of their support needs, and no longer face discrimination. The Strategy contains an ambitious set of initiatives in various areas: accessibility, deinstitutionalization, and independent living, equal participation in education, culture, sports, and tourism, health services, justice, and the global promotion of the rights of persons with disabilities, including supporting their self-advocacy efforts.

In addition to the general aspects described above, there is a cross-cutting aspect in ensuring opportunities for self-advocacy for persons with disabilities: accessibility. The EU Strategy for the Rights of Persons with Disabilities 2021-2030 stipulates that „accessibility to physical and virtual environments, information and communication technologies (ICT), goods and services, including transport and infrastructure, supports rights and is a prerequisite for the full participation of persons with disabilities on an equal basis with others.” (European Commission 2021). In the last decade, the European Union has adopted a series of rules in different areas to make the EU more accessible to persons with disabilities: the European Accessibility Act (which sets common accessibility requirements, covering certain ICT products and services) (EU Directive 882 2019), the Web Accessibility Directive (which sets common accessibility requirements, so that anyone can read, understand, and complete administrative procedures on websites and mobile applications in the public sector) (EU Directive 2102 2016), the Audiovisual Media Services Directive (which relates to sign language, subtitles for persons with hearing impairments, audio support for persons with visual impairments) (EU Directive 1808 2018), and others. For persons with intellectual and psycho-social disabilities, the EU supports initiatives to develop guidelines for adapting information into easy-to-read and plain language (Inclusion Europe 2021).

The European Commission recommends that member states develop and approve mechanisms to ensure the accessibility of physical, informational, and communication environments for persons with disabilities, in accordance with approved standards. EU membership would likely lead to increased attention to and investment in improving accessibility for persons with disabilities in Moldova, as the country would be expected to adhere to EU standards and regulations in this area.

The legal framework of the Republic of Moldova recognizes the importance of physical, informational, and communication accessibility for persons with disabilities. The CRPD and the Law on the Social Inclusion of Persons with Disabilities define accessibility as a set of measures, including identifying and removing obstacles to full, equal access to physical environments, transportation, information, and communication, including information and communication technologies (ICT), and other facilities and services open or provided to the public, both in urban and rural areas. The principle of accessibility is included in national policies and legislative and regulatory acts, but deficiencies are noted in the

implementation of the principle. To date, a stable institutional and organizational framework for ensuring accessibility has not been established.

The start of the process of association of the Republic of Moldova with the European Union entails aligning national policies and practices with European standards, with a potential positive impact on the self-advocacy of persons with disabilities.

Grounds for self-advocacy are also shaped by the global framework of action – *The 2030 Agenda for Sustainable Development* (the Agenda 2030) (United Nations, Transforming our world: the 2030 Agenda for Sustainable Development 2015). Adopted in September 2015 by UN member states, including the Republic of Moldova, the Agenda 2030 aims to forge a fairer, healthier, and more sustainable future for all inhabitants of the planet by 2030.

One of the guiding principles of the Agenda 2030 is „Leaving No One Behind,” emphasising the importance of including and safeguarding vulnerable population groups, including persons with disabilities, in the efforts to implement the Sustainable Development Goals (SDGs). The previous global plan, the Millennium Declaration, did not adequately address the needs of persons with disabilities. Consequently, during the development of Agenda 2030, there were widespread calls from various agencies and organisations, including those representing persons with disabilities, to ensure that the new framework explicitly addresses their issues and needs (Cobley, 2023). As a result, persons with disabilities actively advocate for their interests, leading to a commitment to ensure that everyone is included in the development process (Lee and Perez Bello, 2024).

The Agenda 2030 is driven by 17 overarching SDGs encompassing all crucial aspects of economic growth, social inclusivity, and environmental preservation. Each SDG is accompanied by 169 specific targets, seven of which explicitly address disability. Within a framework that prioritises the needs of persons with disabilities, global and national development initiatives must incorporate concrete measures to tackle barriers to inclusion, such as discriminatory legislation, inaccessible environments, negative attitudes, and stigma. Moreover, there is a pressing need for increased investment in monitoring and evaluating progress towards disability-related SDGs and for enhancing the implementation of laws, policies, and services for persons with disabilities. Agenda 2030 promotes collaboration among governments, international bodies, private enterprises, and civil society, including persons with disabilities, to achieve these objectives and confront global challenges. It emphasizes the crucial role of active and inclusive participation of persons with disabilities, providing them with opportunities to voice their opinions and advocate for their perspectives and needs in decision-making processes that impact their lives.

The role of self-advocacy in the context of implementing the SDGs is crucial. Through self-advocacy, persons with disabilities can ensure that their needs are integrated into development strategies and programs, thereby contributing to the formulation of more relevant and effective policies and actions regarding their inclusion and well-being. Additionally, by expressing their own

experiences and concerns, persons with disabilities can draw attention to issues that may be overlooked in the process of SDG implementation.

In 2015, Moldova pledged to implement Agenda 2030 nationally, followed by adapting the Sustainable Development Goals (SDGs) to its specific context and aligning national policies accordingly (nationalisation of SDGs) (Cancelaria de Stat 2017). A few years later, in 2022, Moldova's Parliament adopted the „European Moldova 2030” National Development Strategy (NDS) (Lege 315 2022), outlining the country's vision and development directions until 2030, closely linked with Agenda 2030, and the Government approved the national framework for monitoring Agenda 2030 implementation, serving as the basis for reporting Moldova's progress domestically and internationally (H G. 953 2022).

Self-advocacy plays a pivotal role in ensuring that the principles of inclusion, equity, and social justice are woven into the implementation of the „European Moldova 2030” NDS. By advocating for themselves, individuals with disabilities can assert their rights to access services and opportunities outlined in the NDS, while also pushing for the elimination of barriers that impede their complete participation and inclusion. Moreover, through self-advocacy, individuals with disabilities can actively encourage authorities and accountable institutions to honour their commitments to advancing the rights and well-being of individuals with disabilities as outlined in the NDS. Therefore, self-advocacy processes significantly contribute to the empowerment and full participation of individuals with disabilities in Moldovan society.

4. Conclusions and Recommendations

In the landscape of disability rights advocacy, the concept of self-advocacy stands as a pivotal mechanism for empowering individuals to assert their rights and participate actively in societal decision-making processes. This article examines the legal provisions that enable self-advocacy within Moldova's legislative framework.

Central to its contribution are several key impacts. First, it provides a comprehensive analysis of existing legal frameworks, offering clarity on the rights of persons with disabilities who engage in self-advocacy efforts. By elucidating these provisions, the article serves as a foundational resource for stakeholders – from policymakers to advocacy groups – seeking to navigate and leverage legal mechanisms in alignment with international human rights standards.

Furthermore, the article advances scholarly discourse by delineating avenues for future research. It prompts longitudinal assessments of legislative impacts, and explorations into intersectional dimensions of disability rights advocacy. These insights pave the way for evidence-based policy interventions that uphold the rights and dignity of all individuals, regardless of ability.

Ultimately, this article underscores its multifaceted impact on advancing the practice of self-advocacy among persons with disabilities in Moldova. It contributes substantively to the ongoing pursuit of inclusive and rights-based approaches to disability rights advocacy.

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Biodata

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