

SUPPORTED DECISION-MAKING FOR PERSONS WITH INTELLECTUAL DISABILITIES – WHAT IS A WAY FORWARD?

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ABSTRACT:

Persons with intellectual disabilities face numerous problems in various areas of life, one of them being a practice of depriving them fully from legal capacity. In this way, they become prevented from making decisions about their own lives, such as where and with whom to live, how to dispose of their own property and income, they become deprived of the right to work, which may result in their institutionalisation in social protection institutions and isolation from the society. This practice is against the provisions of the UN Convention on the Rights of Persons with Disabilities (CRPD). An additional problem is that some persons with intellectual disabilities are non-verbal or minimally verbal and can have problems to write, which poses additional challenges on how to exercise their legal capacity rights. The objective of the paper is to examine international instruments which regulate the right to supported decision making of persons with disabilities and best practices of how this right is governed and exercised in selected European countries. Furthermore, the authors analyse academic literature related to advanced technological methods of augmentative and alternative communication (AAC) to assess to which extent they may be useful to improve communication of people with intellectual disabilities. The authors conclude that advanced AAC technologies may provide a way forward for supported decision making, especially for non-verbal or minimally verbal persons with intellectual disabilities. Although there is no guarantee that every person with intellectual disability will be able to use modern AAC tools, the authors believe that everyone should have an opportunity to try and use it in order to be able “to take his/her live into his/her own hands”.

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Introduction

People with intellectual disabilities face a number of challenges in exercising the right to legal capacity.¹ Legal capacity is the ability of a person to acquire rights and obligations through his/her actions and includes both the right to *legal standing*, i.e. to the capacity to have rights (e.g. the right to property) and *legal agency*, as a capacity to make legal transactions and decisions (e.g. dispose of property and income; the right to choose where and with whom to live; which kind of medical treatment to undertake etc). Whereas the right to *legal standing*, which includes the capacity to be a holder of a right, is guaranteed to all physical and legal persons and cannot be taken away from a person, *legal agency*, as the possibility to exercise these rights is often in dispute for persons with intellectual and mental disabilities. In the General Comment No. 1 of the UN Committee of the Rights of Persons with Disabilities, it is clearly stated that the right to *legal capacity*, includes both the right of *legal standing* and *legal agency* rights (General Comment No. 1, 2014).

A deprivation of legal agency rights may have far-reaching consequences, as it may prevent persons from making key decisions about their own life, including where they will live, with whom they will share their home, it may deprive them of the right to work and how they will manage their assets and income. This practice can result in institutionalisation of persons with intellectual disabilities in social welfare institutions, which further encourages their isolation from the wider community.

Over the past two decades, there has been a world-wide wave of legal reforms regarding the rights of the persons with disabilities, including the right to supported decision making, initiated on the basis of provisions of the UN Convention on the Rights of Persons with Disabilities adopted in 2006. Interestingly enough, Article 12 of the Convention, which grants people with disabilities the right of equal recognition before the law, has been one of the most contested articles both in the academic literature and practice, especially with respect to its application to persons with mental and intellectual disabilities (Duffy, 2023; Sholten et al., 2021; Craigie et al., 2019; Arstein-Kerslake & Flynn, 2015).

An additional problem is the fact that some people with intellectual disabilities, especially those on the autism spectrum, may be non-verbal or minimally verbal and may experience difficulties writing, which creates significant obstacles in terms of exercising their legal capacity rights, even in the case they are granted by a national legislation. For these reasons, it is necessary to investigate not only

¹ There is no single definition of people with intellectual disabilities. One of the most widely accepted definitions is that of the American Association on Intellectual and Developmental Disabilities, in which a person with an intellectual disability is defined as „a person who faces difficulties characterized by significant limitations in intellectual functions and adaptive behavior, and includes numerous everyday social and practical skills“. More information can be found on American Association on Intellectual and Developmental Disabilities (AAIDD) official website: <https://www.aaid.org>.

the best legal options for granting supported decision making of persons with intellectual disabilities, but also to analyse instruments that will enable its effective exercise in practice.

The objective of this paper is twofold: 1) to review international instruments and European national legal frameworks with regard to supported decision making of persons of disabilities and 2) to assess tools that may facilitate supported decision-making process of persons with disabilities in practice, such as the use of modern (high-tech) means of augmentative and alternative communication (AAC) on the basis of the available academic research in this area. The analysis will be underpinned by a review of the theoretical models of disability, as a basis for changes in the legal thought related to the issue of legal capacity of persons with disabilities.

1. Theoretical Models of Disability and Their Relation to Supported Decision Making

Different theoretical models of disability significantly influence how society and legal systems address the issue of depriving persons with disabilities of legal capacity. The oldest model is the medical model, which views disability as an individual problem requiring medical intervention, treating persons with disabilities primarily as patients (Cucić, 2001). This model justifies the deprivation of legal capacity based on medical findings of an individual's inability to make rational decisions. Court rulings on legal capacity often rely on opinions of doctors or psychiatrists, which can lead to the full or partial deprivation of the right to make decisions.

Nowadays, the social model is considered the primary approach, having replaced the medical model. It emphasises the fact that disability is not an individual deficiency but the result of societal barriers. This model views disability through the lens of removing barriers in society and providing access to support (Tatić, 2008). It criticises the practice of fully depriving legal capacity, arguing that this is a consequence of social barriers and prejudices rather than an individual's actual incapacity. Therefore, it advocates for supported decision-making.

The biopsychosocial model of disability combines the core elements of the previous models, recognising that disability may have a biological basis, but societal barriers play a crucial role in creating disability (Tatić, 2008).² This model suggests that the legal capacity of persons with disabilities can be limited, but with the goal of maximising their autonomy in decision-making through appropriate support.

The model of social integration focuses on inclusion and the removal of obstacles that prevent persons with disabilities from fully participating in society

² This model actually represents the interaction of the individual's personal factors and environmental factors. Some of the personal factors are gender, age, coping with stress, education, experience, profession, etc. While environmental factors primarily include social attitudes, support services, architectural barriers, social services, climate, terrain and other factors.

(Holler & Ohayon, 2022). Therefore, legal capacity is seen as essential for enabling autonomous living and equal participation in the community. As a key to achieving this goal, supported decision-making is advocated when making decisions.

Lastly, the capability model (capability approach) is a more recent approach to disability, focusing on the individual capacities and abilities of each person. The aim of this model is to create conditions for equal access to resources, education, and opportunities, enabling persons with disabilities to reach their full potential (Terzi, 2000). This model opposes the full deprivation of legal capacity, asserting that every individual, regardless of their disability, can make decisions with appropriate support.

When we consider all these models, we may conclude that the view on depriving persons with disabilities of legal capacity has significantly evolved over time. Modern approaches recognise the rights of persons with disabilities to autonomy, emphasising the provision of adequate support to enable them to make decisions in line with their needs and desires. The deprivation of legal capacity is often based on a diagnosis (e.g., intellectual or psychosocial disability), without considering individual circumstances or abilities. The issue with this approach lies in its generalisation, which fails to recognize the variability of abilities among individuals with the same diagnosis.

2. Legal Capacity and Supported Decision Making for Persons with Disabilities in International Instruments

The legal capacity of persons with disabilities is a focal issue in various international instruments, particularly those related to human rights. The UN Special Rapporteur on Torture has emphasised that depriving persons with disabilities of their legal capacity can lead to their torture and abuse (UN, Special Rapporteur on Torture, 2008, para. 50).

The International Covenant on Civil and Political Rights, in Article 16, guarantees every individual the right to legal personality, that is, the right to be recognised as a legal person. More precisely, this article recognises that all individuals, regardless of their physical or mental abilities, have the right to be legal subjects, to possess rights and obligations protected by the legal system (International Covenant, 1966). Although this instrument does not directly address legal capacity, its provisions on equality before the law and prohibition of discrimination are significant for protecting the rights of persons with disabilities.

The Convention on the Rights of Persons with Disabilities (CRPD), which is based on the social model of disability, is the most important international document regulating this issue. The Article 12 of the Convention recognises the right of persons with disabilities to be regarded equal before the law, which is a prereq-

quisite for enjoying all other rights guaranteed by this Convention. It also obliges States Parties to ensure that persons with disabilities equally enjoy legal capacity, regardless of the degree of their disability. This article represents a significant advancement in the rights of persons with disabilities (particularly those with intellectual disabilities) as it requires them to be recognized as legal entities capable of independently managing their rights, and has also been one of the most contested Articles of the Convention (Duffy, 2023). Article 12 of the Convention has a key role in the realisation of many other guaranteed rights including: the right to making decisions on participation in the development and implementation of laws and policies concerning persons with disabilities (Article 4(3) of the Convention); access to courts (Article 13); the right to freedom and security (Article 14); making decisions about place and lifestyle (Article 19); family and partnership decisions (Article 23); educational choices (Article 24); and decisions related to health care (Article 25).

General Comment No. 1 of the UN Committee on the Rights of Persons with Disabilities is a key international instrument that clarifies the meaning of Article 12. One of the main highlights of General Comment No. 1 is the distinction between legal capacity and mental capacity, where it is clearly stated that *mental capacity*, as an individual decision making ability is not a prerequisite for *legal capacity*. This is often considered as a major shift in understanding of legal capacity in international context (Arstein-Kerslake & Flynn, 2015). General Comment No. 1 underscores that legal capacity must be guaranteed to everyone, regardless of the type or degree of disability, and that states must provide an adequate system of support that will enable persons with disabilities to make their own decisions.

In order to successfully implement the provisions of the Convention, the countries which have signed the Convention have to replace “substituted decision-making” with “supported decision-making”. General Comment No. 1 does not, however, provide a precise definition of the term “supported decision-making”, which can be justified for several reasons. This is a rapidly evolving area, and the lack of a clear definition reflects the awareness that persons with disabilities, especially those with intellectual disabilities, are unique and require individualised support. Some persons with disabilities, on the other hand, may not want any support at all. For some, the main obstacle may be the deprivation of legal capacity. Once this restriction is removed, the barrier disappears, allowing them to fully exercise their rights and obligations independently. Other persons may need much more substantive support in the decision making process, depending on an individual case.

Some authors distinguish between “supported decision-making” and “assisted decision-making”. “Supported decision-making” pertains not only to how decisions are made but also seeks to redefine the understanding of how assessment of intellectual or mental capacity should be carried out (Browning et al., 2014). This

approach appears to be the kind of approach that could enable the implementation of a “paradigm shift” in a more comprehensive way, as it distances legal capacity from the traditional individual assessment of cognitive ability (Stefanovic & Beauchamp, 2019).

Supported decision-making can take both formal and informal forms, but needs to be non-intrusive and dependent solely on the will of the person with a disability. The advantage of an informal form of support lies in the fact that there is a higher probability that the providers of this support will know the person well and will be in their life for a longer time. Formal support structures may be subject to greater safeguards and a guarantee of “independence”, but they have a serious risk of becoming too professionalised, creating another barrier that is not easy to overcome when speaking to people with mental disabilities (Flynn & Arstein-Kerslake, 2014). The development of a system of supported decision-making is also called for by the UN Guidelines on Deinstitutionalisation, provided in the General Comment 5 of the CPDR. Nevertheless, in practice it appears to be difficult to fully implement supported decision making, as even most progressive national legislations in the world reflect some kind of individual assessment of cognitive ability (Stefanovic & Beauchamp, 2019).

At the regional level in Europe, there are several international instruments that indirectly address the issue of depriving persons with intellectual disabilities of their legal capacity. One of the most important is the Recommendation R(99)4 of the Committee of Ministers, which emphasises the need for proportionality and the maximum preservation of legal capacity of an individual (Recommendation R(99)4, 1999).

The Council of Europe adopted an Action Plan on the Rights of Persons with Disabilities for the period of 2017–2023, whose main goal was to further promote the rights of persons with disabilities, focusing on the practical implementation of the CRPD at the national level (Council of Europe, 2016). The key priorities of this new plan included promoting deinstitutionalisation and support for independent living in the community, as well as ensuring that infrastructure, public services, and digital technology are accessible to persons with disabilities.

The European Union does not have direct regulations specifically addressing the deprivation of legal capacity of persons with disabilities. However, this aspect is regulated through a series of instruments and policies that deal with the rights of persons with disabilities in a broader context, especially in connection with human rights and non-discrimination. The discussion on the legal capacity of persons with disabilities is closely linked to a set of fundamental rights guaranteed by the Charter of Fundamental Rights of the European Union. Primarily, where key principles of equality and non-discrimination are emphasised, contained in Article 21, which guarantees non-discrimination, Article 20, which provides for equality before the

law, and Article 26, which promotes the integration of persons with disabilities (EU Charter on Fundamental Rights, 2012). When discussing EU instruments, it is also necessary to emphasise that the European Disability Strategy 2021-2030 promotes a human rights-based approach to disability, including reforming guardianship systems and encouraging member states to implement supported decision-making instead of depriving legal capacity.³

3. Legal Framework on Supported Decision Making of Persons with Disabilities in selected European countries

Although all EU member states have ratified the CRPD, only a couple of them have fully reformed their legal frameworks on deprivation of legal capacity. An increasing number of countries are approaching legislative reforms in accordance with CRPD principles, thus transitioning from guardianship systems to supported decision-making systems in their national legislation to a higher or lower degree. One positive example in this respect is Germany's reform of its legal capacity laws, which is based on the concept of supported decision-making (Brosey, 2021).

The Law on Reform of the Guardianship and Custody adopted in 2021 (which came into force on January 1, 2023) contains the most comprehensive changes in the field of legal capacity rights in Germany since 1992 (Gesetz zur Reform des Vormundschafts und Betreuungsrechts, 2021). It is important to note that by this law several other laws were amended, with the focus on the substantive part of the German Civil Code (BGB),⁴ in whose 4th volume (Family Law) the chapter on guardianship for adults was deleted and replaced by new legislation (§§ 1896–1908 i BGB).

The changes are primarily aimed at strengthening the self-determination and autonomy of people in need of guardianship support in line with Article 12 of the UN Convention on the Rights of Persons with Disabilities (Section 1821 BGB 2023). The new legislation clearly states that guardianship primarily ensures support for the person under guardianship in managing his or her affairs through his or her own self-determined actions and that the guardian may only use the means of representation to the extent that it is necessary (Section 1823 BGB 2023). Under

³ The European Strategy for the Rights of Persons with Disabilities 2021-2030 aims to improve the quality of life of persons with disabilities through the promotion of equal opportunities, accessibility, and independent living. The strategy relies on the principles of equality and non-discrimination contained in the Charter of Fundamental Rights of the EU and the Treaty on Functioning EU. See more Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions: Union of Equality – Strategy for the Rights of Persons with Disabilities 2021-2030.

⁴ Civil Code, the version promulgated on 2 January 2002 (*Federal Official Gazette* [Bundesgesetzblatt] I page 42, 2909; 2003 I page 738), last amended by Article 1 of the Act of 10 August 2021 (*Federal Official Gazette* I p. 3515).

the previous legislation, a guardian had to look after the affairs of the person under guardianship in a way that was in a guardian's view the best interests of the person under guardianship. Now, although a guardian makes a formal decision, the wishes of the person under guardianship or their presumed will are at the forefront of the guardian's actions (Section 1816 BGB 2023). This means that a guardian is obliged to align his/her actions more closely with the wishes of the person being cared for to the fullest extent possible. Furthermore, a person being cared for should be better informed and more involved in all stages of the care process, in particular in the court decision on whether and how to appoint a guardian and in the selection of the specific guardian (Section 1862, BGB 2023). The amendments clearly emphasise that the decisions of individuals take precedence and that appointed guardians ("Betreuer") or advisors must support the person's wishes, except in rare cases where a decision might pose a serious risk to the individual's life or health (Schnellenbach et al., 2023). Decisions involving a significant risk to the person may be reviewed by the court, but with respecting the will of the person whenever possible. Judicial supervision will also be more focused on determining the wishes of the person under guardianship (Schnellenbach et al., 2023). The new legislation further places an emphasis on suitability of guardians, as professional guardians will have to register with a care authority in the future and demonstrate that they meet minimum personal and professional suitability requirements. Breaches of duty by the guardian, particularly those that impair the self-determination of the person under guardianship, are enlisted and sanctioned by the law (Schnellenbach et al., 2023). As the changes of the guardianship legislation started to be implemented only in 2023, up to now there has been no assessment of its effects and challenges in practice.

Many European countries use combined or flexible systems, where the court can decide to limit a person's legal capacity only in certain areas, such as finances or healthcare. Thus, for example, in France, guardianship for persons with disabilities who are deprived of legal capacity operates through two primary models: *tutelle* (full guardianship) and *curatelle* (partial guardianship). Under *tutelle*, a guardian manages key life decisions, especially financial ones, while the person retains some autonomy in everyday choices, such as personal rights, with larger decisions requiring judicial approval. *Curatelle* offers a more limited role for the guardian, assisting the person only in significant legal or financial matters. The system aims to balance protection with individual autonomy, using minimal intervention proportional to the person's needs. Italy uses a similar model known as *amministrazione di sostegno* (support in decision-making), introduced by Law No. 6/2004. This system allows the appointment of an administrative guardian to assist persons with partial difficulties, but it is based on the principle of minimal restriction of their rights and decision-making capacities. In Hungary, after the *Alajos*

Kiss v. Hungary case of the European Court of Human Rights, full deprivation of legal capacity was abolished, as part of wider changes to the country's constitution, which came into force in 2012. In Sweden, a model of supported decision-making known as *god man* (good man) is used, where the person with a disability retains their rights but receives support from a legal guardian in legal matters (Fridström Montoya, 2019). This guardianship is flexible and adaptable to the needs of the person with a disability. There is also the *förvaltare* option, where the guardian can take full control of the person's affairs, but only in exceptional cases. The system favours minimal interference in the individual's rights, making the guardian an advisor rather than a decision-maker (Fridström Montoya, 2019). The Dutch law allows a more flexible model that favours supported decision-making. *Curatele* (full guardianship) is a more restrictive measure, while *bewind* (partial control over finances) and *mentorschap* (mentorship support) are more commonly used.

In Serbia, legal capacity can be partially or completely deprived from persons with mental or intellectual disabilities only on the basis of their disability, which is against the EU Convention on the Rights of Persons with Disabilities (Krstić & Beker, 2017). The deprivation of legal capacity is regulated by the Family Law and the Law on Non-Contentious Proceedings, which contain different yet substantively similar provisions regarding deprivation of legal capacity. Although there have been some minor improvements of the legal framework introduced by the amendments to the Law on Non-Contentious Proceedings in 2014 (following the European Court of Human Rights' case of *Salaontaji – Drobnjak vs. Serbia* of 2009) there has been no substantive change of the legal framework which would ensure supported decision making of people with disabilities (Jović Prlainović, 2020). Although the amendments to the Family Law were prepared in order to, *inter alia*, replace full deprivation of legal capacity with partial deprivation of legal capacity, these changes have still not been adopted (Preliminary draft, 2021).

4. How to enable supported decision making for non-verbal and minimally verbal adults - the use of AAC as a way forward?

Changes of legal frameworks regarding deprivation of legal capacity and introducing supported decision making in many European countries are encouraging signs of progress in this area, but also raise important questions on how to enable supported decision-making process in practice. This is especially an issue if a person with intellectual disability or other kind of disability is non-verbal or minimally verbal. Spoken language can be a significant barrier for individuals with intellectual disabilities, especially those who are on the autism spectrum. If a person is not able to talk, it is more likely that an issue of deprivation of legal capacity may be raised, especially in not yet reformed legal systems.

The use of alternative and augmentative communication (AAC) support was for a long time considered as a “last resort” for children and adults who did not develop functional speech.⁵ There appears to be a suspicion on the side of occupational therapists towards the use of AAC, and often also parents, as they believe that if a child is offered a means of communication (e.g. a communicator), he will not make an effort to use spoken language. This hypothesis is nowadays being contested. But let us first return to the meaning and definition of AAC.

Augmentative and alternative communication (AAC) entails all of the ways of communication that do not include talking. The word “augmentative” denotes anything that can be added to someone’s speech, while the word “alternative” encompasses all the means that could be used instead of speech (ASHA, 2024). Although there are a many different types of AAC, the usual distinction is made between low tech and high-tech models. Low-tech options include gestures, writing, drawing, spelling words by pointing to letters, pointing to pictures (e.g. Picture Exchange Communication System – PECS), or written words. High-tech options include using different kinds of software, where words are coupled with pictures that produce sounds, and are hence often called a speech-generating devices (ASHA, 2024).

While high-tech options of AAC were not widely available in the past, there has been a rapid development of technologies used for augmentative and alternative communication and an increasing development and availability of these devices over the past decade. With the increased use of AAC by people with intellectual disabilities, research on autism and AAC has also increased.

A number of studies have proved the benefits of AAC use for children with intellectual disabilities and autism for supporting communicative function. For example, meta-analysis led by Ganz in 2012, has shown numerous advantages of AAC using for improvement of communication skills (Ganz at al., 2012). Another previously conducted research by Miller showed that although the therapist and parents may be concerned about the use of AAC, as a potential detriment to speech, in many cases speech has also improved over the course of using AAC in great majority (89%) of cases (Miller at al., 2006). A systematic review of research into AAC as a tool to increase social – communication function, led by Logan, showed positive effects of AAC on communication and the need for further socially valid research in this area (Logan at al., 2017).

Over the past decade, there has been a growing body of research on the use of

⁵ Nowadays, significant efforts in some countries, such as USA, are placed on community based early intervention programmes for children with autism and intellectual disabilities (from around 3-6 years of age), with a focus on gaining speech, but with mixed results. A longitudinal study conducted by Rose *at al* in 2016 showed that more than half of the children who entered the early intervention programmes with minimal speech exited the programme without a significant speech improvement and around quarter of them has significant communication problems after completing the programme (Rose at al., 2016).

AAC by adolescents and adults, which has also shown the need for developing overall communication skills for people with intellectual disabilities rather than focusing on speech alone. A systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder led by Holyfield has shown clear AAC benefits for adolescents and adults with autism spectrum disorder and urged for more research on this topic, in order to improve lives of adolescents and adults with autism (Holyfield et al., 2017). The research of Zisk and Dalton (2019) on the use of AAC for adults has explored, *inter alia*, barriers to AAC use, and found that there is a lack of awareness of relevant options, misconceptions about who AAC supports are for and high cost of certain high-tech AAC instruments. They recommend to prioritise development of overall communication skills of people with intellectual disabilities rather than to focus solely on speech. This is due to the finding that autistic adults, including those who talk, may not always be able to meet all their communication needs with speech alone, as their speaking skills may be intermittent, unreliable, and/or insufficient (Zisk & Dalton, 2019). The authors also recommend usage of new communication technologies in order to support development of communication skills for autistic adults.

A recent small preliminary study of the experiences of speaking autistic adults who use AAC conducted by Donaldson et al. (2021), has shown similar findings. Participants of the study (6 of them) reported that they discovered AAC as adults, as when they were children they were not offered alternative means of communication. It is interesting that participants also pointed out that they were independently seeking alternative ways of communicating because “speech did not feel normal, natural, and/or successful” (Donaldson et al., 2021). Many participants felt that they were forced to communicate by the use of speech, often by family members and employees of speech language services (Donaldson et al., 2021). The authors conclude that alternative forms of communication, such as AAC, should be introduced to children at a much younger age in order to have an opportunity to better express themselves and also to adults who do not have developed their communication skills to a desirable extent (Donaldson et al., 2021). This may be a significant “paradigm shift” in using the AAC which can help communication not only of children, but also adolescents and adults enabling them to secure their legal capacity and have the power over their own lives.

Conclusion

The right to supported decision making has relatively recently become one of the key internationally recognised human rights of persons with disabilities. Although rather “young” right, which struggles to find its way to be embedded and guaranteed by national legislations, it is a particularly important human right, as it is intrinsically linked to other human rights, such as the right of choosing a place

to live, the right to give consent to a medical treatment, the right to work etc. It is not in dispute that full deprivation of legal capacity may have very serious consequences, such as involuntary institutionalization of a persons in social welfare or medical institutions and can lead to significant neglect, abuses and violation of human rights. Women with intellectual disabilities are especially vulnerable in this situation, as the full loss of legal capacity deprives them of their right to make decisions regarding their reproductive health and makes them at risk of gender-based violence, especially if they are institutionalised in the social care institutions.

The key question which this article has tried to answer is how to secure the supported decision making of persons with disabilities, especially those with intellectual disabilities?

Looking from a lawyers' point of view, the first step would be to change national legal frameworks to adopt the concept of "supported decision making" instead of the prevailing "substitute decision making" or "best interest" approach and align national legislation with the CRPD provisions. As our analysis has shown, all key international instruments which govern this area do recognise the need for enabling all people with disabilities the right to supported decision making, whether they have adequate mental capacity or capability or not. Given that up to now (October, 2024) 164 countries have signed the CRPD, it may be argued that most of the countries in the world do have an obligation to integrate the provisions of the convention in their legal framework. This, however, appears to be a rather slow process, that needs to be speeded up in many countries, including those of the European continent. German model, which focuses on strengthening the self-determination and autonomy of people in need of decision making support, may serve as a good example on how to reform national legal frameworks to be in line with CRPD requirements.

The second step, which should be done in parallel with the reform of the legal framework, is to ensure that supported decision making become a reality by developing tools which can help people with disabilities, especially those who cannot talk and/or have intellectual disability, to exercise their rights. Many legal reforms have proved to be just a "dead letter on the paper" if they are not supported with adequate means for implementation of the legal changes. In this respect, our review of literature on the use of AAC shows that a use of high tech AAC devices may provide a promising path towards implementation of the supported decision making rights of people with intellectual disabilities in practice and warrants continuation of similar type of empirical research on this subject in the future. Conducting this type of research, however, necessitates that people with intellectual disabilities, especially those who are non-verbal or minimally verbal have access to modern AAC devices, which should be adapted to their needs both in terms of content and accessibility in terms of their costs. Awareness of the AAC benefits should also be

presented to educators and parents of people with intellectual disabilities. Although there is no guarantee that every person with intellectual disability will be able to use modern AAC tools, we believe that everyone should have an opportunity to try to use it and make every effort to exercise his/her supported decision making rights to the fullest.

REFERENCES

- AHSA, Augmentative and Alternative Communication. (2024). <https://www.asha.org/public/speech/disorders/aac/>. Accessed 1 October 2024.
- Arstein-Kerslake, A., & Flynn, E. (2015). The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law. *The International Journal of Human Rights*, 20(4), 471-490. <https://doi.org/10.1080/13642987.2015.1107052>
- Brosey, D. (2021). Aspects of the Reform of the German Legislation of Betreuung. https://www.americanbar.org/groups/senior_lawyers/resources/voice-of-experience/2010-2022/aspects-reform-german-legislation-betreuung/. Accessed 30 September 2024.
- Browning, M., Brigby, C., & Douglas, J. (2014). Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 34-45. <https://doi.org/10.1080/23297018.2014.902726>
- Charter of Fundamental Rights of the European Union (2012). Official Journal of the European Union, C 326/391. <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX%3A12012P%2FTXT>
- Civil Code in the version promulgated on 2 January 2002 (Federal Law Gazette [Bundesgesetzblatt] I page 42, 2909; 2003 I page 738), last amended by Article 1 of the Act of 10 August 2021 (Federal Law Gazette I p. 3515). https://www.gesetze-im-internet.de/english_bgb/english_bgb.html
- Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions: Union of Equality – Strategy for the Rights of Persons with Disabilities 2021-2030. EUR-Lex. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:52021DC0101>
- Council of Europe Disability Strategy 2017-2023. (2016). <https://www.coe.int/en/web/disability/strategy-2017-2023>
- Craigie, J., Bach, M., Gurbai, S., Kanter, A., Kim, S., Lewis, O., & Morgan, G. (2019). Legal capacity, mental capacity and supported decision-making: Report from a panel event. *International Journal of Law and Psychiatry*, 62, 160-168. <https://doi.org/10.1016/j.ijlp.2018.09.006>.
- Cucić, V. (ur). (2001). *Osobe sa invaliditetom i okruženje*. CPA.
- Donaldson, A., Corbin, E., & McCoy, J. (2021). Everyone Deserves AAC: Preliminary Study of the Experiences of Speaking Autistic Adults Who Use Augmentative and Alternative Communication. *Perspectives of the ASHA Special Interest Group*, 6(2), 315-326. https://doi.org/10.1044/2021_PERSP-20-00220
- Duffy, J. (2023). *Mental Capacity, Dignity and the Power of International Human Rights*, Cambridge University Press.
- Flynn, E., & Arstein-Kerslake, A. (2014). Legislating personhood: Realising the right to support in exercising legal capacity. *International Journal of Law in Context*, 10(1), 81-104. <https://doi.org/10.1017/S1744552313000384>
- Fridström Montoya, T. (2019). Unterstützte Entscheidungsfindung im schwedischen Recht – der »Gute Mann«: Held oder Schurke im Licht der UN-BRK?. In M. Zinkler, C. Mahlke & R. Marschner, *Selbstbestimmung und Solidarität* (pp. 222-232). Psychiatrie Verlag.
- Ganz, J., Pustejovsky, J., Reichle, J., Vannest, K., Foster, M., Pierson, L., & Smith, S. (2022). Participant characteristics predicting communication outcomes in AAC

- implementation for individuals with ASD and IDD: a systematic review and meta-analysis. *Augmentative and Alternative Communication*, 39(1), 7–22. <https://doi.org/10.1080/07434618.2022.2116355>
- Ganz, J., Earles-Vollrath, T., Heath, A., Parker, R., Rispoli, M., Duran, J. (2012). A meta-analysis of single case research studies on aided augmentative and alternative communication systems with individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(1), 60–74. <https://doi.org/10.1007/s10803-011-1212-2>
- General Comment No. 1 - Article 12: Equal recognition before the law. (2014). UN Committee on the Rights of Persons with Disabilities. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-1-article-12-equal-recognition-1>
- General Comment No. 5 (2017) on living independently and being included in the community (2017). UN Committee on the Rights of Persons with Disabilities. <https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FP-PRiCAqhKb7yhsnbHatvuFkZ%2Bt93Y-3D%2Baa2q6qfzOy0vc9Qie3KjjeH3GA0srJgyP8IRbCjW%2FiSqmYQHwGkfikC-7stLHM9Yx54L8veT5tSkEU6ZD3ZYxF-wEgh>
- Gesetz zur Reform des Vormundschafts und Betreuungrechts, Bundesgesetzblatt Jahrgang 2021 Teil I Nr. 21. https://www.bgbl.de/xaver/bgbl/start.xav?startbk=Bundesanzeiger_BGBI&start=%2F%2F%2A%5B%40attr_id=%27bgbl121s0882.pdf%27%5D#__bgbl__%2F%2F%5B%40attr_id%3D%27bgbl121s0882.pdf%27%5D__1735660438625
- Holler, R., & Ohayon, Y. (2022). Understanding Disability Policy Development: Integrating Social Policy Research with the Disability Studies Perspective. *Social Policy and Society*, 23(3), 1–16. <https://doi.org/10.1017/S1474746422000367>
- Holyfield, C., Drager, K., Kremkow, J., & Light, J. (2017). Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *Augmentative and Alternative Communication*, 33(4), 201–212. <https://doi.org/10.1080/07434618.2017.1370495>
- International Covenant on Civil and Political Rights. (1966). UN General Assembly. <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-civil-and-political-rights>
- Jović Prlainović, O. (2020). Međunarodni standardi u nacionalnom sistemu poslovne sposobnosti osoba sa invaliditetom. U D. Čeranić (ur.), *Pravo, tradicija i promjene* (pp. 89–107). Pravni fakultet Univerziteta u Istočnom Sarajevu.
- Kiss, A. (2015). End to automatic voting ban for people placed under guardianship. <https://www.coe.int/en/web/impact-convention-human-rights/-/end-to-automatic-voting-ban-for-people-placed-under-guardianship>. Accessed 1 October 2024.
- Krstić, I., & Beker, K. (2017). *Situaciona analiza: poslovna sposobnost i osobe sa invaliditetom u Srbiji*. MDRI-S. <https://www.mdri-s.org/wp-content/uploads/2017/10/SitAn-Poslovna-sposobnost-i-osobe-sa-invaliditetom-u-Srbiji.pdf>
- Law on Non-Contentious Procedure, *Official Gazette of the SRS*, 25/82 and 48/88; 46/95 – other law; 18/2005 – other law; 85/2012; 45/2013 – other law; 55/2014; 6/2015; 106/2015 – other law; 14/2022.
- Logan, K., Iacono, T., & Trembath, D. (2017). „A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder“, *Augmentative and Alternative Communication*, 33(1), 51–64. <https://doi.org/10.1080/07434618.2016.1267795>
- Millar, D., Light, J., & Schlosser, R. (2006). The impact of augmentative and alternative communication intervention on the speech production of individuals with developmental disabilities: a research review. *Journal of Speech, Language, and Hearing Research*, 49(2), 248–64. [https://doi.org/10.1044/1092-4388\(2006/021\)](https://doi.org/10.1044/1092-4388(2006/021))
- Ministère de la Justice. (2024). La tutelle et la curatelle - Mesures de protection des majeurs. <https://www.justice.fr/themes/tutelle-curatelle>. Accessed 15 October 2024.
- Preliminary draft of the Law on amendments of the Family Law (Serbia). (2021). *Paragraf*. <https://www.paragraf.rs/dnevne-vesti/260721/260721-vest10.html>
- Recommendation No. R(99)4 on Principles concerning the Legal Protection of Incapa-

- ble Adults. (1999). Committee of Ministers of the Council of Europe. [https://www.coe.int/t/dg3/healthbioethic/texts_and_documents/rec\(99\)4e.pdf](https://www.coe.int/t/dg3/healthbioethic/texts_and_documents/rec(99)4e.pdf)
- Rijksoverheid (n.d.). Wat zijn de verschillen tussen curatele, bewind en mentorschap? <https://www.rijksoverheid.nl/onderwerpen/curatele-bewind-en-mentorschap/vraag-en-antwoord/verschillen-curatele-beschermingsbewind-en-mentorschap>. Accessed 15 September 2024.
- Rose, V., Trembath, D., Keen, D., & Paynter, J. (2016). The proportion of minimally verbal children with autism spectrum disorder in a community-based early intervention programme. *Journal of Intellectual Disability Research*, 60(5), 464-77. <https://doi.org/10.1111/jir.12284>
- Scholten, M., Gather, J., & Vollmann, J. (2021). Equality in the Informed Consent Process: Competence to Consent, Substitute Decision-Making, and Discrimination of Persons with Mental Disorders. *The Journal of Medicine and Philosophy*, 46(1), 108-136, <https://doi.org/10.1093/jmp/jhaa030>
- Schnellenbach, A., Normann-Scheerer, S., Giers, M., & Thielke, U. (2023). *Betreuungsrecht für die Praxis - Das neue Recht ab 1.1.2023* (Buch 3). FamRZ.
- Stefanović, L., & Beauchamp, E. (2019), *Kanadski model odlučivanja uz podršku kao moguća alternativa režimu starateljstva u Srbiji*. MDRI-S.
- Tatić, D. (2008). *Zaštita ljudskih prava osoba sa invaliditetom*. Službeni glasnik.
- Terzi, L. (2020). Capability and Disability. In E. Chiappero-Martinetti, S. Osmani, & M. Qizilbash (eds.), *The Cambridge Handbook of the Capability Approach* (pp. 544-561) Cambridge University Press.
- UN Convention of the Rights of Persons with Disabilities. (2006). UN General Assembly. <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Zisk, A., & Dalton, E. (2019). Augmentative and Alternative Communication for Speaking Autistic Adults: Overview and Recommendations. *Autism Adulthood*, 1(2), 93-100. <https://doi.org/10.1089/aut.2018.0007>

PODRŠKA U DONOŠENJU ODLUKA ZA OSOBE S INTELEKTUALNIM TEŠKOĆAMA – KOJIM PUTEM NAPRIJED?

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APSTRAKT:

Osobe s intelektualnim teškoćama suočavaju se s brojnim problemima u raznim područjima života, a jedan od njih je praksa potpunog lišavanja poslovne sposobnosti. Na taj način, spriječeni su donositi odluke o vlastitom životu, poput izbora mjesta i osobe s kojom će živjeti, raspolaganja vlastitom imovinom i prihodima, te bivaju lišeni prava na rad, što može rezultirati institucionalizacijom u ustanovama socijalne zaštite i izolacijom od društva. Ova praksa je u suprotnosti s odredbama Konvencije UN-a o pravima osoba s invaliditetom (CRPD). Dodatni problem predstavlja činjenica da su neke osobe s intelektualnim teškoćama neverbalne ili minimalno verbalne te imaju poteškoće u pisanju, što postavlja dodatne izazove u ostvarivanju njihovih prava na poslovnu sposobnost. Cilj ovog rada je ispitati međunarodne instrumente koji reguliraju pravo na podržano donošenje odluka osoba s invaliditetom te primjere dobre prakse kako se ovo pravo uređuje i ostvaruje u odabranim evropskim zemljama. Nadalje, autori analiziraju akademsku literaturu vezanu za napredne tehnološke metode augmentativne i alternativne komunikacije (AAC) kako bi procijenili u kojoj mjeri one mogu doprinijeti poboljšanju komunikacije osoba s intelektualnim teškoćama. Autori zaključuju da napredne AAC tehnologije mogu pružiti put naprijed za podržano donošenje odluka, posebno za neverbalne ili minimalno verbalne osobe s intelektualnim teškoćama. Iako ne postoji garancija da će svaka osoba s intelektualnim teškoćama moći koristiti moderne AAC alate, autori vjeruju da bi svako trebao imati priliku isprobati i koristiti ih kako bi mogao “uzeti svoj život u svoje ruke”.

Ključne riječi:

osobe s intelektualnim teškoćama, podržano donošenje odluka, augmentativna i alternativna komunikacija (AAC)