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# **Comparison of legal systems in access to justice for persons with intellectual disabilities in the following countries:**

- Bulgaria**
- Finland**
- France**
- Hungary**
- Ireland**

1



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## Table of contents

Executive Summary .....	3
1. Introduction .....	7
1.1 Report Overview .....	7
1.1 Background.....	8
1.2 Overview of Relevant Human Rights Standards.....	11
1.3 Guiding Principles.....	15
1.4 Methodology .....	16
2. Comparative Analysis of Legal Systems .....	20
2.1 Legal guardianship and alternatives – current situation and proposed reforms.....	20
2.1.1 Legal capacity restrictions in numbers.....	20
2.1.2. Guardianship regimes affecting decision-making powers of adults with intellectual disabilities .....	22
2.1.3. Regimes under which the legal capacity of adults with intellectual disabilities remains intact in theory.....	26
2.1.4. Challenging appointments, decisions, review/removal of guardians.....	37
2.2 Adults with intellectual disabilities in the justice system.....	43
3. Trainings for guardians and support persons .....	63
4. Trainings for officials in the justice system.....	66
5. Conclusions .....	68
Annex I: Annotated Bibliography .....	71
Annex II: Glossary of Terms.....	94
Annex III: Guiding Principles Table .....	97
Annex IV: Template for data gathering from partner countries .....	101



## Executive Summary

“(T)he human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.”<sup>1</sup>

‘Access to Justice for Persons with Intellectual Disabilities’ (AJuPID) is a project that aims to identify how five European countries – Bulgaria, Finland, France, Hungary and Ireland – provide for equal recognition before the law and access to justice for people with intellectual disabilities. Particular attention is paid to adults with intellectual disability who are under substituted decision-making arrangements, such as guardianship laws or wards of court systems. The aim is to promote a shift to supported decision-making and accessible justice in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Current laws and policies in each country are outlined and compared, including consideration of the role of legal guardians, general support persons and judicial staff. The report provides a comparative examination of the barriers to access to justice in each jurisdiction and at the level of the European Union (EU). This includes highlighting successful initiatives that can be seen to enhance the legal capacity of adults with intellectual disability, including those under current guardianship arrangements and to foster their access to justice on an equal basis with others.

3

The research is the culmination of data gathering and research by all AJuPID partners. Chief investigation was undertaken by the Centre for Disability Law and Policy, NUI Galway in Ireland, and KU Leuven in Belgium. All country partners contributed to data gathering (namely: Hand in Hand Foundation in Hungary, KVPS in Finland, FEGAPEI in France, NFVB in Ireland, Foundation NET in Bulgaria and EASPD). By comparing national reviews and EU-level activity, the report addresses a gap in literature on how to implement rights to legal capacity and access to justice for persons with intellectual disabilities.

### Research Design

The report analyses EU regional activity against reviews of law and policy in each of the five partner countries. The reviews include information on any currently proposed reforms to the systems of legal guardianship (including both plenary and partial guardianship). Particular reference was paid to the relevant legal proceedings (for example, statutory review of guardianship, revocation of guardianship, property, and choice of where and with whom to live) wherever possible. This included:

<sup>1</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 34, UN Doc. No. CRPD/C/GC/1, adopted at the 11<sup>th</sup> Session (April 2014) para. 3.



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- a) law, policy and practice on persons with intellectual disabilities rights' to seek legal assistance and to directly instruct legal representation;
- b) legal standing of persons with intellectual disabilities to initiate a court or tribunal action (in civil and administrative cases) or to make complaints to dispute resolution forums, including arbitration and mediation mechanisms, and recourse to domestic complaints mechanisms of last resort, including Ombudsman's offices;
- c) legal mechanisms or practices in the justice system which require judges to personally meet with people with intellectual disabilities who are the subject of a case and regulations for this process;
- d) rules of evidence and procedure which enable people with disabilities to give direct testimony in court – and any regulations or reported cases involving the use of interpreters, or other communication supports – including augmented and alternative communication, facilitated communication, or total communication, and;
- e) procedural accommodations which enable persons with intellectual disabilities to participate in court proceedings – including the design of court rooms and proceedings, and the use of video testimony.

According to the UN Committee on the Rights of Persons with Disabilities (CRPD Committee), the CRPD mandates the *replacement* of systems of substituted decision-making with supported decision-making.<sup>2</sup> As such, the researchers were concerned with the options for challenging guardianship arrangements, given that guardianship constitutes substituted decision-making. Particular attention was therefore paid to:

- a) procedures for challenging the appointments of guardians, specific decisions of guardians, or review/removal of guardians;
- b) introduction of less restrictive alternatives to guardianship to support individuals in the exercise of their legal capacity (without removing their legal capacity);
- c) data on numbers of cases where individuals:
  - have successfully and unsuccessfully challenged the appointment of guardians;
  - had guardians removed (comparing to failure of removal of guardians); and
  - had legal capacity restored (comparing to failure of restoration of legal capacity).

### Conclusions and Recommendations

Overall, the research highlights the interrelated nature of guardianship law and policy, and access to justice for adults with intellectual disability. The five jurisdictions under consideration vary as to the specific nature of their guardianship systems and in the available mechanisms for achieving access to justice. Yet in all countries, it is clear that governments are uncertain as to how they can fully realise the 'paradigm shift' of the CRPD in achieving the transition from substituted to supported decision-

<sup>2</sup> CRPD Committee, 'Concluding Observations', [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5) last accessed 23 June 2014



making. Even governments who are more advanced in this respect have remained cautious in developing alternatives that would fully replace substituted decision-making. Hence, abandoning substituted decision-making as a cornerstone of laws relating to persons with intellectual disability remains an ongoing challenge. Indeed, a principle finding of this report is that there remains a considerable ‘implementation gap’ in achieving access to justice and equal recognition before the law for adults with intellectual disability.

To address this gap, the report makes a number of recommendations which are summarised below.

1. That governments consider implementing ongoing mechanisms to replace the framework of guardianship, mental capacity assessments and ‘best interests’ decision-making with a supported decision-making regime. This could include:
  - a. undertaking law reform to replace assessments of mental capacity with the provision of supports to exercise legal capacity;
  - b. prioritising the will and preference of the relevant person with intellectual disability rather than a ‘best interests’ model;
  - c. developing supported decision-making in policy and practice by drawing on the emerging range of good practices being promoted internationally;
  - d. making clear information and resources available to support people to challenge guardianship orders and arrange alternative supports that do not restrict legal capacity.
2. That governments consider implementing ongoing mechanisms to promote access to justice for people with intellectual disabilities. This could include:
  - a. auditing specific barriers in access to justice, for example, the lack of reasonable accommodations regarding speech and language for people with intellectual disabilities in legal proceedings;
  - b. collecting data on the types of support that people with disabilities are requesting or availing of in legal proceedings;
  - c. ensuring that legal proceedings – from courtrooms to administrative tribunals and reporting mechanisms – are accessible to people with disabilities in general;
  - d. reforming laws so that denial of reasonable accommodation is deemed by law to be an act of disability-based discrimination.

In conclusion, it is important to emphasise that guardians, curators, and tutors are often considered as supportive, empowering and enabling towards adults with intellectual disabilities. However, according to the interpretation of the CRPD Committee, the over-arching legal framework for appointing guardians (and similar substitute decision-makers) violates the right to equal recognition before the law. Further, there is ample evidence to show that, in practice, guardianship provisions provide a troubling discretionary power to guardians in directing the lives of those for whom they are



legally empowered to make decisions.<sup>3</sup> The paradoxical role of guardianship in this transitional period continues to challenge people with disabilities and their families, policymakers, professionals and others wishing to promote the rights of persons with disabilities. This report makes inroads to resolving these tensions.

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<sup>3</sup> See generally, Mental Disability Advocacy Centre, 'Legal Capacity in Europe Legal Capacity in Europe: A Call to Action to Governments and to the EU,' Author, October 2013 <[mdac.info/sites/mdac.info/files/legal\\_capacity\\_in\\_europe.pdf](http://mdac.info/sites/mdac.info/files/legal_capacity_in_europe.pdf)> viewed 10 December 2014



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## 1. Introduction

‘Access to Justice for Persons with Intellectual Disabilities’ (AJuPID) is a project aiming to improve knowledge about and foster access to justice for adults with intellectual disabilities in five participating countries; Bulgaria, Finland, France, Hungary and Ireland. The project seeks to address the fact that many adults with intellectual disabilities are placed under guardianship-type measures,<sup>4</sup> and there is a lack of information about how current legal systems provide adults with intellectual disabilities with the right to effective access to justice with appropriate accommodations.<sup>5</sup> There is also a dearth of information on how to implement the UN Convention on the Rights of Persons with Disabilities (CRPD) and on the implications of the rights to legal capacity and access to justice of persons with intellectual disabilities for legal guardians, support persons and judicial staff. This report aims to address this gap.

This report analyses the extent to which adults with intellectual disabilities have access to the justice system and what role the guardians and support persons have in the proceedings. A key element of this analysis is comparing the theory and practice collected from the five countries with the provisions of the CRPD including its authoritative interpretation by the UN treaty bodies, such as the CRPD Committee.

### 1.1 Report Overview

The report will be structured in the following way. The introductory chapter will provide general information about the research design. Section 1.2 will provide background to the general area and Section 1.3 will provide further context by giving an overview of relevant human rights standards, at the international and regional level. From this basis in international human rights law Section 1.4 will proceed by setting out the guiding principles for the report. These principles provide a high-level conceptual overlay by which to examine the current law, policy and practice in each partner country, and to help to envisage new ways forward. The introduction chapter will then end with a section that details the methodology used in this report.

Chapter 2 will explore the different legal systems in each of the five partner countries – Bulgaria, Ireland, France, Finland and Hungary. It will compare and contrast jurisdictions and examine how access to justice and the right to equal recognition before the law is or is not being secured under current law and policy. Throughout, the report also seeks to convey the various alternative arrangements that are being developed in each country, so as to capture innovative ideas in law and policy.

<sup>4</sup> See eg, Mental Disability Advocacy Center, *Legal Capacity in Europe. A Call to Action to Governments and to the EU*, Budapest, MDAC, 2013

<sup>5</sup> According to a study from 2007, ‘access of people with intellectual disability to rights and justice is by no means guaranteed [in eight European countries: Spain, Sweden, Poland, Germany, France, Belgium, the Netherlands and Slovenia].’ Inclusion Europe, *Justice, Rights and Inclusion for People with Intellectual Disability*, 2007, 30, see <<http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1279&context=gladnetcollect>> last accessed on 19 September 2014



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Chapter 3 focuses on existing or proposed elements of compulsory training for legal guardians and support persons on the rights of adults with intellectual disabilities, including communication supports that exist in current law and policy in each country.

Chapter 4 focuses on existing or proposed elements of compulsory training for officials in the justice system (lawyers, judges, clerks, notaries, etc.) on the rights of persons with intellectual disabilities and effective communication techniques.

The concluding chapter, Chapter 5, draws together the major themes of the report as a whole, and advances both specific and general recommendations for achieving rights to access justice and to have equal recognition before the law for adults with intellectual disability.

For ease of understanding, Annex II contains a glossary of terms, which provides a useful reference in understanding the terminology of the field.

## 1.1 Background

The catalyst for the AJuPID project is the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Two key Articles in particular, inform this study: Article 12 (the right to legal capacity and equal recognition before the law) and Article 13 (access to justice). In the terms of the United Nations Committee on the Rights of Persons with Disabilities (the CRPD Committee), ‘the recognition of the right to legal capacity is essential for access to justice in many respects.’<sup>6</sup> The interconnectedness of these fundamental rights is explored with reference to domestic and EU-level law and policy throughout this report.

The EU ratified the CRPD in 2010 and is obliged to comply in those areas which fall under EU competences. In 2010 the European Commission clearly indicated that ‘rights such as equal recognition before the law (Article 12) and access to justice (Article 13)’ was a ‘key problem area’ for the EU.<sup>7</sup> The European Disability Strategy 2010-2020 underlines that ‘EU action will support and supplement national policies and programmes to promote equality, for instance by promoting the conformity of Member State legislation on legal capacity with the UN Convention.’<sup>8</sup> This section of the Strategy also outlines the aim to “(e)radicate discrimination on grounds of disability in the EU.”<sup>9</sup>

Articles 12 and 13 have also been highlighted as priority activities in other regional European activity. The Council of Europe, for example, in its 2006-2015 Disability Action Plan, urges Member States of the Council of Europe to ensure, inter alia, that:

<sup>6</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 34, UN Doc. No. CRPD/C/GC/1, adopted at the 11<sup>th</sup> Session (April 2014).

<sup>7</sup> European Commission, Commission staff working document, Accompanying the Communication from the Commission to the European Parliament, the Council, the European Economic Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. Brussels, 15.11.2010. SEC(2010) 1323 final. Para 3.1.2.2

<sup>8</sup> European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. Brussels, 15.11.2010 COM(2010) 636 final SEC(2010) {SEC(2010) 1323} {SEC(2010) 1324}. Para 2.1.3

<sup>9</sup> Ibid.





...the right of persons with disabilities to make decisions is not limited or substituted by others, that measures concerning them are individually tailored to their needs and that they may be supported in their decision making by a support person.<sup>10</sup>

Further, states must ensure that:

...people placed under guardianship are not deprived of their fundamental rights (not least the rights to [...] bring legal proceedings [...]), and, where they need external assistance so as to exercise those rights, that they are afforded appropriate support, without their wishes or intentions being superseded.<sup>11</sup>

Directives to implement supported decision-making are reflected elsewhere in general EU law and policy activity, including reports by the Commissioner for Human Rights of the Council of Europe,<sup>12</sup> judgments of the European Court of Human Rights,<sup>13</sup> and documents of the European Union Agency for Fundamental Rights.<sup>14</sup>

There appears to be uncertainty among States Parties to the CRPD as to implementing Articles 12 and 13 of the CRPD. This is particularly the case with regards to guardianship law. Governments face multi-level challenges, including legal, economic and attitudinal barriers when it comes to implementation of the rights to legal capacity and access to justice for persons with disabilities. This would suggest that there is a considerable *implementation gap* regarding Articles 12 and 13 of the CRPD. The research in this report is directed to addressing this gap in law and policy.

For its part, the CRPD Committee has repeatedly directed governments to review guardianship and to take actions to replace guardianship laws with supported decision-making.<sup>15</sup> The first General Comment of the CRPD Committee elaborates on this directive, and indicates that guardianship laws inherently restrict the legal capacity of persons with disability on an unequal basis with others.<sup>16</sup> The European Commission has also considered the need to separate guardianship and supported decision-making processes. In the European Commission Staff Working Document accompanying the European Disability Strategy 2010-2020, for example, a commissioned study by the European Foundation Centre recommended that:

<sup>10</sup> Council of Europe - Parliamentary Assembly, Access to rights for people with disabilities and their full and active participation in society, Resolution 1642 (2009). Adopted by the Assembly on 26 January 2009, Para 7.1.

<sup>11</sup> Ibid. Para 7.2.

<sup>12</sup> See eg. Commissioner for Human Rights of the Council of Europe, 'The right of people with disabilities to live independently and be included in the community. Issue Paper commissioned and published by Thomas Hammarberg, Council of Europe Commissioner for Human Rights' CommDH/IssuePaper(2012)3 12 March 2012; Commissioner for Human Rights of the Council of Europe, 'WHO GETS TO DECIDE? Right to legal capacity for persons with intellectual and psychosocial disabilities' Council of Europe, CommDH/IssuePaper(2012)2.

<sup>13</sup> See eg. *Lashin v Russia* (2012) ECHR 63; *MS v Croatia* (2013) ECHR 378; *Sýkora v The Czech Republic*; *DD v Lithuania* (2012) ECHR 10; *Stanev v Bulgaria* (2012) ECHR 46; *Seal v UK* (2010) ECHR 1976.

<sup>14</sup> Fundamental Rights Agency, 'Legal capacity of persons with intellectual disabilities and persons with mental health problems,' Vienna, July 2013 <<http://fra.europa.eu/en/publication/2013/legal-capacity-persons-intellectual-disabilities-and-persons-mental-health-problems>> viewed 3 September 2013.

<sup>15</sup> CRPD Committee, 'Concluding Observations',

<[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5)> viewed 23 June 2014

<sup>16</sup> Committee on the Rights of Persons with Disabilities, above n 1



Legislation should be revised to abolish restrictive guardianship laws and policies. Measures should be taken to ensure access to supported decision-making, whereas effective safeguards to ensure that assistants do not abuse their position should be established.<sup>17</sup>

The report emphasized the need to distinguish guardianship and supported decision-making processes:

A large number of Member States continue to operate restrictive guardianship laws and policies. Where legislative reforms provide for personal assistants to support people with disabilities in decision-making, the distinction between such assistants and guardians is not clear enough.<sup>18</sup>

At the same time, the European Foundation Centre describe the establishment of the support model of Article 12 as ‘a complex task’ requiring ‘careful consideration of different proposals’ which are ‘clearly determined in consultation with key actors, and (which) should be gradually implemented.’<sup>19</sup> Inclusion Europe have recommended that States Parties ‘set up a plan to implement gradually the newly adopted supported decision-making system: ...traditional guardianship measures on the basis of appropriate law reforms should be reviewed for all cases and should progressively be replaced by the supported decision-making system.’<sup>20</sup>

This incrementalist position contrasts with the CRPD Committee’s directive that the ‘right to equality before the law has a long history of recognition as a civil and political right.’<sup>21</sup> Under international human rights law, civil and political rights are subject to immediate realisation and not progressive realisation. As such the CRPD Committee directs States Parties to ‘take steps to immediately realize the rights within Article 12, including the right to support for the exercise of legal capacity.’<sup>22</sup>

The fact that this discrepancy exists between the CRPD Committee’s directives and domestic law reform activity should not come as a surprise. It is generally agreed that no jurisdiction in the world can claim to be fully compliant with Article 12 of the CRPD.<sup>23</sup>

Having provided background to the aims of this project, the next section will provide an outline of human rights standards on the rights to recognition of legal capacity and access to justice.

<sup>17</sup> European Commission, above n 2, 31

<sup>18</sup> Ibid

<sup>19</sup> European Foundation Centre, *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities*, VC/2008/1214 (author 2010) 93

<sup>20</sup> They also direct States Parties to ‘(r)evue all national laws in light of Article 12 and to ensure that the right to self-determination and to equal recognition before the law without discrimination on the basis of disability is enshrined in the law.’ Inclusion Europe, *Key Elements of a System for Supported Decision-Making: Position Paper of Inclusion Europe: Adopted at the General Assembly 2008* (Author 2008) 6 <<http://www.inclusion-europe.org/documents/Position%20Supported%20Decision%20Making%20EN.pdf>> viewed 10 October 2012

<sup>21</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 34, UN Doc. No. CRPD/C/GC/1, adopted at the 11<sup>th</sup> Session (April 2014).

<sup>22</sup> Ibid (emphasis added).

<sup>23</sup> See eg, European Commission, above n 3, 25.



## 1.2 Overview of Relevant Human Rights Standards

This section will provide a short overview of the standards on legal capacity and access to justice by focusing on the CRPD at the level of the United Nations, the commitments of the European Union, and the Council of Europe level standards.

### CRPD – United Nations

Three out of the five countries, namely Bulgaria, France and Hungary ratified the CRPD and the remaining two countries, Finland and Ireland, signed the CRPD.<sup>24</sup> Both Finland and Ireland have already indicated their intention to ratify the CRPD and amend their legislation to ensure compliance with the CRPD before ratification.<sup>25</sup>

Having and enjoying legal capacity are the prerequisites of being recognised as right-holders in all aspects of life including in the field of the right to access to justice.<sup>26</sup> As such, the CRPD obliges States to

- recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life;<sup>27</sup>
- take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity;<sup>28</sup>
- ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages;<sup>29</sup>
- promote appropriate training for those working in the field of administration of justice, including police and prison staff.<sup>30</sup>

Although many legal measures exist concerning the rights to legal capacity and access to justice in the European Union, Council of Europe and in the United Nations,<sup>31</sup> the CRPD's purpose is to

<sup>24</sup> Bulgaria ratified the CRPD on 22 Mar 2012; France ratified the CRPD on 18 Feb 2010; Hungary ratified the CRPD on 20 Jul 2007. Finland and Ireland signed the CRPD on 30 Mar 2007. France however made a 'declaration' with regard to Article 29 of the CRPD, and implicitly to Article 12, stating that legal capacity may be restricted in accordance with the modalities provided for in article 12 of the Convention. The European Union has also become a State Party to the CRPD and by the 'formal confirmation' the EU is obliged to comply with the Convention in those areas which fall under EU competences.

<sup>25</sup> European Union Agency for Fundamental Rights (FRA), *Fundamental rights: challenges and achievements in 2012*, Annual Report 2012, Luxembourg, Publications Office of the European Union, 2013, 140

<sup>26</sup> For a detailed analysis of the right to access to justice see: Eilíonóir Flynn and Anna Lawson, 'Disability and Access to Justice in the European Union: Implications of the United Nations Convention on the Rights of Persons with Disabilities' in Lisa Waddington, Gerard Quinn and Eilíonóir Flynn (Eds), *European Yearbook of Disability Law: Volume 4*. Intersentia, 2013, 7-43

<sup>27</sup> CRPD Article 12(2)

<sup>28</sup> Ibid Article 12(3)

<sup>29</sup> Ibid Article 13(1)

<sup>30</sup> Ibid Article 13(2)

<sup>31</sup> For an overview of these instruments see: European Union Agency for Fundamental Rights (FRA), *Access to Justice in Europe: an overview of challenges and opportunities*, Luxembourg, Publications Office of the European Union, 2011; European Union Agency for Fundamental Rights (FRA), *Legal capacity of persons with intellectual disabilities and persons with mental health problems*, Luxembourg, Publications Office of the European Union, 2013.



emphasise the universality of these rights by claiming that *all persons with disabilities shall be guaranteed the full and equal enjoyment of all human rights and fundamental freedoms*.<sup>32</sup>

The CRPD Committee underlines that ‘the recognition of the right to legal capacity is essential for access to justice in many respects.’<sup>33</sup> Thus, discriminatory denial of legal capacity and denial of the right to support in the exercise of legal capacity is a violation not only of Article 12 (Equal recognition before the law) and 5 (Equality and non-discrimination) of the CRPD,<sup>34</sup> but may violate Article 13 (Access to justice) too. Failure to provide reasonable accommodation, which is a form of discrimination, may also violate the right to access to justice. Moreover, Article 9 (Accessibility) of the CRPD plays a key role when it comes to the exercise of the right to access to justice since it provides for access to information and communication; which involves, *inter alia*, accessible multimedia as well as written, audio and plain-language. If these accessible formats are not available for persons with intellectual disabilities, both Articles 9 and 13 will be violated.

Indeed, barriers to access to justice are numerous<sup>35</sup> and include lack of available and affordable legal representation that is reliable; inadequacies in existing laws effectively protecting persons with disabilities; lack of adequate information; limited popular knowledge of rights; lack of adequate legal aid systems and limited public participation in reform programmes.<sup>36</sup> As long as persons with disabilities face either these kinds of obstacles or others to their participation in the justice system, they will be unable to assume their full responsibilities as members of society or vindicate their rights.<sup>37</sup>

The UN Committee on the Rights of Persons with Disabilities has reviewed 13 States parties<sup>38</sup> as of September 2014 and have found that *there is a considerable implementation gap regarding articles 12 and 13 of the CRPD*. Concluding observations of the CRPD Committee show that *States do not have a clear idea as to implementing these articles of the CRPD and governments are facing multi-level challenges*, including legal, economic, and attitudinal barriers when it comes to implementation of the rights to legal capacity and access to justice for persons with disabilities. The CRPD Committee has realised this implementation gap and formulated recommendations on article 12 to each of the 13 States whose compliance it has so far reviewed. Access to justice-related recommendations were made by the CRPD Committee in almost all of the Concluding Observations, and States have been repeatedly directed to replace guardianship and other systems of substituted decision-making with supported decision-making. Finally, the CRPD Committee’s first General Comment, on Article 12 of the CRPD, was designed explicitly to resolve ongoing confusion about the right to equal recognition before the law, including particularly, the right to support for the exercise of legal capacity on an

12

<sup>32</sup> CRPD Cf. Article 1

<sup>33</sup> CRPD Committee, *General Comment on Article 12 of the CRPD*. Adopted on 11 April 2014. CRPD/C/GC/1. Para 38

<sup>34</sup> Ibid 32

<sup>35</sup> Martín Abregú groups these barriers into two categories: operational (e.g. the quality of legal assistance has been traditionally related to the payment of lawyers’ fees) and structural (e.g. the lack of awareness of those vulnerable groups of their right to claim their rights). Martín Abregú, ‘Barricades or Obstacles: The Challenges of Access to Justice’ in Rudolf V. Van Puymbroeck (ed), *Comprehensive Legal and Judicial Development: Toward an Agenda for a Just and Equitable Society in the 21<sup>st</sup> Century*, Washington, World Bank, 2001, 53-69

<sup>36</sup> United Nations Development Program, *Access to Justice, Practice Note* (New York: United Nations 2004) 4

<sup>37</sup> Stephanie Ortoleva, ‘Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System,’ *ILSA Journal of International and Comparative Law* (2011) 17:2, 286

<sup>38</sup> These States parties are Tunisia, Spain, Peru, Argentina, Hungary, China, Paraguay, Austria, El Salvador, Australia, Sweden, Costa Rica, and Azerbaijan.



equal basis with others. Nonetheless, this General Comment is too recent to be seen to have driven changes in law and policy since formal adoption by the CRPD Committee. As such, States continue to face a considerable ‘implementation gap’ regarding legal capacity and access to justice for people with disabilities.

The CRPD Committee emphasises that overcoming access to justice related barriers are relevant in the context of the rights of persons with disabilities and clarifies that

- persons with disabilities must be recognized as persons before the law with equal standing in courts and tribunals;
- persons with disabilities shall have access to legal representation on an equal basis with others;
- persons with disabilities shall have the opportunity to challenge interference with their right to legal capacity;
- persons with disabilities shall have the opportunity to defend their rights in court;
- persons with disabilities must be granted legal capacity to testify on an equal basis with others;
- persons with disabilities must be provided with access to support in the exercise of legal capacity and;
- the judiciary must be trained and made aware of their obligation to respect the legal capacity of persons with disabilities, including legal agency and standing.<sup>39</sup>

### European Union

13

The European Union ratified the CRPD in 2010 and became a State party to the Convention. Thus, the EU is obliged to comply with the CRPD in those areas which fall under EU competences. In its ‘Report on the implementation of the UN Convention on the Rights of Persons with Disabilities by the European Union’ the European Commission underlined that the EU

- has no competence to regulate the question of legal capacity; this rests with the Member States;<sup>40</sup>
- shares competences with the Member States in the area of freedom, security and justice which is relevant for the implementation of Article 13 of the CRPD.<sup>41</sup>

In 2010 the European Commission clearly indicated that “there is not much quantitative Europe-wide information about rights such as equal recognition before the law (Article 12) and access to justice (Article 13), but there are clear indications that this is a key problem area.”<sup>42</sup> (Once again, it is the findings of this study that it would be an effective initial step to build a proper statistic report at the national and European level of current guardianship practices). The European Disability Strategy 2010-2020 underlines that “EU action will support and supplement national policies and programmes

<sup>39</sup> CRPD Committee, General Comment on Article 12 of the CRPD, Paras 38-39

<sup>40</sup> European Commission, Commission staff working document, Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union. Brussels, 5.6.2014. SWD(2014) 182 final, para 68 [http://ec.europa.eu/justice/discrimination/files/swd\\_2014\\_182\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf) last accessed 2 September 2014.

<sup>41</sup> Ibid, para 71

<sup>42</sup> European Commission, Commission staff working document, Accompanying the Communication from the Commission to the European Parliament, the Council, the European Economic Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. Brussels, 15.11.2010. SEC(2010) 1323 final. Para 3.1.2.2



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to promote equality, for instance by promoting the conformity of Member State legislation on legal capacity with the UN Convention.”<sup>43</sup> In its initial plan to implement the European Disability Strategy 2010-2020, the European Commission pledged, inter alia, to “raise awareness among [Member States] of the need to improve accessibility of courts and police buildings” and to “raise awareness among [Member States] on the need for proper assistance regarding access to legal documents and procedures.”<sup>44</sup>

Even before 2010, the Commission called on Member States several times to share good practices especially in the field of implementation of the right to legal capacity.<sup>45</sup> The Commission’s engagement to legal capacity related issues is shown by the funding provided for pre-accession countries under the [EU-PERSON project](#) which aims to increase the capacity of Balkan (and Turkish) Civil Society Organisations to advocate for and monitor law reforms in the area of legal capacity.<sup>46</sup> Concerning the right to access to justice for persons with disabilities, the EU adopted several legal measures in the field of criminal proceedings,<sup>47</sup> however civil and administrative procedures were not reflected on by these legal instruments.

### Council of Europe

Member States of the Council of Europe are explicitly urged by the 2006-2015 Disability Action Plan, adopted by the Committee of Ministers before the adoption of the CRPD, to “ensure effective access to justice for persons with disabilities on an equal basis with others.”<sup>48</sup> In 2009, the Parliamentary Assembly invited Member States to “guarantee that people with disabilities retain and exercise legal capacity on an equal basis with other members of society.”<sup>49</sup> In order to achieve this, the Parliamentary Assembly underlined that Member States have to ensure, inter alia, that

- the right of persons with disabilities to “make decisions is not limited or substituted by others, that measures concerning them are individually tailored to their needs and that they may be supported in their decision making by a support person;”<sup>50</sup>
- “...people placed under guardianship are not deprived of their fundamental rights (not least the rights to [...] bring legal proceedings [...]), and, where they need external assistance so as to exercise those rights, that they are afforded appropriate support, without their wishes or intentions being superseded.”<sup>51</sup>

<sup>43</sup> European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. Brussels, 15.11.2010. COM(2010) 636 final. Para 2.1.3

<sup>44</sup> European Commission, Commission staff working document, above n 3

<sup>45</sup> See Disability High Level Group reports from 2008 and 2009

<sup>46</sup> For information on the EU-PERSON project, see <http://www.eu-person.com/> last accessed 2 September 2014.

<sup>47</sup> European Commission, Commission staff working document, Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union, Brussels, 5.6.2014. SWD(2014) 182 final, Paras 72-77.

<sup>48</sup> Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015 (adopted by the Committee of Ministers on 5 April 2006). Para 3.12.2.i

<sup>49</sup> Council of Europe - Parliamentary Assembly, Access to rights for people with disabilities and their full and active participation in society, Resolution 1642 (2009), adopted by the Assembly on 26 January 2009.

<sup>50</sup> Ibid, Para 7.1

<sup>51</sup> Ibid, Para 7.2





The European Convention on Human Rights (ECHR) does not mention the right to legal capacity; however, article 8 of the ECHR provides a right to respect for one's private and family life. The European Court of Human Rights (ECtHR) issued a Factsheet on mental health in 2013 and highlighted how the question of legal capacity falls under article 8 of the ECHR.<sup>52</sup> Regarding the right to access to justice, article 6 of the ECHR plays a key role which protects the right to a fair trial. The ECtHR Factsheet on 'Persons with disabilities and the ECHR' lists several cases where article 6 of the ECHR was violated as a result of restriction or denial of legal capacity and placement under guardianship.

In the case of *Shtukaturv v. Russia*<sup>53</sup> the applicant was deprived of his legal capacity and was placed under plenary guardianship. Mr Shtukaturv was not notified about the proceedings which were launched in order to place him under guardianship; he was denied to appeal his placement under guardianship because he lacked legal standing to initiate legal proceedings. He was placed in a psychiatric hospital against his will and during his stay in this institution he was even denied to meet a lawyer. The ECtHR held that there had been a violation of both Articles 6 and 8 of the ECHR.

In the more recent case of *Stanev v. Bulgaria*<sup>54</sup> the applicant's legal capacity was restricted and consequently he was placed under partial guardianship. Mr Stanev was sent to live in a social care institution against his will. Although he made several requests to his guardian in order for him to be released from partial guardianship and to be able to leave the social care institution, his requests were constantly refused. Mr Stanev could not apply directly to a court to seek restoration of his legal capacity. The ECtHR held that there had been a violation of Article 6 of the ECHR.

15

### 1.3 Guiding Principles

In order to measure legislation and practice, the following human rights standards are identified based on the CRPD and the CRPD Committee's interpretation:

- i. persons with intellectual disabilities enjoy legal capacity on an equal basis with others;
- ii. enjoyment of legal capacity by persons with intellectual disabilities is ensured in all aspects of life including the right to access to justice;
- iii. persons with intellectual disabilities are provided with access to support in the exercise of legal capacity in all areas of life including the right to access to justice;
- iv. support measures respect the person's rights, will and preferences;
- v. effective access to justice is ensured for persons with intellectual disabilities;
- vi. procedural and age-appropriate accommodations are ensured for persons with intellectual disabilities;
- vii. reasonable accommodations are ensured for persons with intellectual disabilities in the field of access to justice;

<sup>52</sup> European Court of Human Rights, Factsheet – Mental Health, May 2013, [http://www.echr.coe.int/Documents/FS\\_Mental\\_health\\_ENG.pdf](http://www.echr.coe.int/Documents/FS_Mental_health_ENG.pdf) last accessed 2 September 2014

<sup>53</sup> *Shtukaturv v. Russia*, Application No 44009/05, judgment of the Chamber of 27 March 2008

<sup>54</sup> *Stanev v. Bulgaria*, Application No. 36760/06, judgment of the Grand Chamber of 17 January 2012



- viii. persons with intellectual disabilities are enabled to take part in proceedings as direct and indirect participants
- ix. persons with intellectual disabilities are provided with access to information and communication
- x. the judiciary is trained about their obligation to respect the rights of persons with intellectual disabilities.

## 1.4 Methodology

This research was undertaken by compiling and comparing literature regarding domestic law in each country and in international human rights law. The literature reviews spanned between the dual focus of the AJuPID project on 1) equal recognition before the law, including the right to exercise legal capacity on an equal basis with others (Article 12 CRPD), and 2) access to justice (Article 13 CRPD).

This AJuPID project report analyses EU regional activity against reviews of law and policy in each of the five partner countries, as compiled by AJuPID civil society partner organisations. The reviews include information on any currently proposed reforms to the systems of legal guardianship (including both plenary and partial guardianship). Particular attention was paid to the following:

- d) procedures for challenging the appointments of guardians, specific decisions of guardians, or review/removal of guardians;
- e) introduction of less restrictive alternatives to guardianship to support individuals in the exercise of their legal capacity (without removing their legal capacity);
- f) data on numbers of cases where individuals:
  - have successfully and unsuccessfully challenged the appointment of guardians;
  - had guardians removed (comparing to failure of removal of guardians); and
  - had legal capacity restored (comparing to failure of restoration of legal capacity).

Particular reference was paid to the relevant legal proceedings (for example, statutory review of guardianship, revocation of guardianship, property, and choice of where and with whom to live) wherever possible. This included:

- f) law, policy and practice on persons with intellectual disabilities rights' to seek legal assistance and to directly instruct legal representation;
- g) legal standing of persons with intellectual disabilities to initiate a court or tribunal action (in civil and administrative cases) or to make complaints to dispute resolution forums, including arbitration and mediation mechanisms, and recourse to domestic complaints mechanisms of last resort, including Ombudsman's offices;
- h) legal mechanisms or practices in the justice system which require judges to personally meet with people with intellectual disabilities who are the subject of a case and regulations for this process;
- i) rules of evidence and procedure which enable people with disabilities to give direct testimony in court – and any regulations or reported cases involving the use of



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- interpreters, or other communication supports – including augmented and alternative communication, facilitated communication, or total communication, and;
- j) procedural accommodations which enable persons with intellectual disabilities to participate in court proceedings – including the design of court rooms and proceedings, and the use of video testimony.

By comparing national reviews and EU-level activity, the report addresses a gap in literature on how to implement rights to legal capacity and access to justice for persons with intellectual disabilities.

The *national level literature review* included academic literature, and grey literature. While academic literature is formally published and is widely accessible, grey literature is not published commercially and this is why its accessibility can be limited. Academic literature may include:

- legal texts
- judgments of national courts<sup>55</sup>
- Books including monographs, book of essays etc.
- Academic journals with different types of articles (journal article, book review, research report etc.)

In our case ‘grey literature’ includes:

- civil society documents (e.g. policy papers, submissions, statements, shadow reports submitted to UN Treaty bodies especially to the CRPD Committee<sup>56</sup> and to other bodies e.g. European Committee of Social Rights,<sup>57</sup> etc.).
- government documents (e.g. studies, State reports submitted to UN Treaty bodies especially to the CRPD Committee and to other bodies e.g. European Committee of Social Rights, etc.)
- other (e.g. documents of ombudspersons).

17

The literature review was designed to assist in the following respects:

- understanding how persons with intellectual disabilities are supported in the fields identified under the material scope of the project;
- having a clear picture about the current legal system on guardianship and supported decision-making;
- identifying gaps in the legislative and the practical (implementation of legal measures) levels;
- comparing and contrasting different authors’ views on the research topic;
- identifying patterns or trends in the literature;
- highlighting questions left unanswered;

<sup>55</sup> It can be argued that legal texts and court judgments belong to academic literature and/or to grey literature. See: <https://dspace.library.uvic.ca/bitstream/handle/1828/3221/2010-01-GL11Lines-AreLegalTexts.pdf?sequence=1> last accessed 2 September 2014

<sup>56</sup> United Nations Office of the High Commissioner for Human Rights, ‘Sessions for CRPD - Convention on the Rights of Persons with Disabilities’ [http://tbinternet.ohchr.org/\\_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD](http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD) last accessed 2 September 2014

<sup>57</sup> See eg. European Committee of Social Rights (ECSR), Committee of Europe, [http://www.coe.int/t/dghl/monitoring/socialcharter/ecsr/ecsrdefault\\_en.asp](http://www.coe.int/t/dghl/monitoring/socialcharter/ecsr/ecsrdefault_en.asp) last accessed 2 September 2014



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- explaining how the AJuPID Project can contribute to improve the right to access to justice for persons with intellectual disabilities;
- considering how those acting as legal guardians can contribute to a shift toward supported decision-making as a basis for law and policy including the abolition of partial and full guardianship; and,
- considering how to replace regimes of substitute decision-making by supported decision-making.

On the basis of these concerns, a template was created for undertaking a comparative review of the literature regarding each country. National partners in the AJuPID project were then invited to use the template in order to conduct a literature review regarding relevant national law and policy and (where required) translate the review into English.

In order to research and compile literature at the European level, EASPD was invited to undertake a similar literature view, using the same template. The methodology for the Europe-wide review was the same as the national-level reviews, yet the literature was broader. Additional literature included legal texts of the EU and the CoE, documents of the Commissioner for Human Rights of the CoE,<sup>58</sup> judgments of the European Court of Human Rights,<sup>59</sup> and relevant documents of the European Union Agency for Fundamental Rights.<sup>60</sup> The compilation of comparison of the literature review and the legal systems were then undertaken with a view to:

- explaining the existing “legal protection laws and models” including reform initiatives
- comparing and contrast different authors’ views on the research topic
- group authors who draw similar conclusions
- note areas in which authors are in disagreement
- identify patterns or trends in the literature
- highlight gaps in the legislative and the implementation levels
- identify questions left unanswered
- conclude by summarising what the literature says.<sup>61</sup>

The template used for the national and regional analysis invited researchers to first survey relevant national and regional reports from existing research in the field,<sup>62</sup> and provide any new information or updates (from 2010) on particular issues. The template then asked for information on any currently proposed reforms to the systems of legal guardianship (including both plenary and partial guardianship). Particular attention was paid to the following:

<sup>58</sup> See eg. <http://www.coe.int/en/web/commissioner/documents;jsessionid=27DC229863690C47440C5FBE916D6161> last accessed 12 September 2014

<sup>59</sup> See eg. [http://hudoc.echr.coe.int/sites/eng/Pages/search.aspx#{"documentcollectionid2":\["GRANDCHAMBER","CHAMBER](http://hudoc.echr.coe.int/sites/eng/Pages/search.aspx#{) accessed 12 September 2014

<sup>60</sup> See eg. <http://fra.europa.eu/en/publication/2013/legal-capacity-persons-intellectual-disabilities-and-persons-mental-health-problems> last accessed 2 September 2014

<sup>61</sup> C.f. <http://www.unimelb.libguides.com/content.php?pid=87165&sid=648279> last accessed 2 September 2014

<sup>62</sup> For existing research in the field, see Academic Network of European Disability Experts, ‘DOTCOM’ <http://www.disability-europe.net/dotcom> last accessed 2 August 2014.



- g) Procedures for challenging the appointments of guardians, specific decisions of guardians, or review/removal of guardians;
- h) introduction of less restrictive alternatives to guardianship to support individuals in the exercise of their legal capacity (without removing their legal capacity);
- i) data on numbers of cases where individuals:
  - have successfully and unsuccessfully challenged the appointment of guardians;
  - had guardians removed (comparing to failure of removal of guardians); and
  - had legal capacity restored (comparing to failure of restoration of legal capacity).

Partners were then invited to provide information on the participation of people with intellectual disabilities in the justice system and provide any updates from existing reports on the specific issues in civil and administrative proceedings. Particular reference was paid to the relevant legal proceedings (statutory review of guardianship, revocation of guardianship, property, choice of where and with whom to live) wherever possible, including:

- a) law, policy and practice on persons with intellectual disabilities rights' to seek legal assistance (including eligibility for free legal aid) and to directly instruct legal representation;
- b) legal standing of persons with intellectual disabilities to initiate a court or tribunal action (in civil and administrative cases) or to make complaints to dispute resolution forums, including arbitration and mediation mechanisms, and recourse to domestic complaints mechanisms of last resort, including the Ombudsman/National Human Rights Institutions;
- c) legal mechanisms or practices in the justice system which require judges to personally meet with people with intellectual disabilities who are the subject of a case and regulations for this process;
- d) rules of evidence and procedure which enable people with disabilities to give direct testimony in court – and any regulations or reported cases involving the use of interpreters, or other communication supports – including augmented and alternative communication, facilitated communication, or total communication;
- e) procedural accommodations which enable persons with intellectual disabilities to participate in court proceedings – including the design of court rooms and proceedings, and the use of video testimony.

For a full list of the questions asked of national partners, see Annex IV, which sets out the template for data gathering from partner countries. Once the national reports and the regional overview were compiled, it was possible to undertake the comparative analysis.

The contents of the literature used in this report are threaded throughout the entire report and are contained in a standalone annotated bibliography, which is found at Annex I, and which provides a table of existing literature compiled from the five countries and from the European level.



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## 2. Comparative Analysis of Legal Systems

This Chapter will explore the different legal systems in each of the five countries – Bulgaria, Ireland, France, Finland and Hungary. It will compare and contrast jurisdictions and examine how access to justice and the right to equal recognition before the law is or is not being secured under current law and policy. Throughout the report also seeks to convey the various alternative arrangements that are being developed in each country, so as to capture innovative ideas in law and policy.

Section 1 focuses on current measures on legal guardianship, substituted decision-making and supported decision-making in each country. Section 2 focuses on adults with intellectual disabilities in the justice system and will consider how access to justice is being secured under current arrangements, and how it is being denied to people with intellectual disabilities under the current framework.

### 2.1 Legal guardianship and alternatives – current situation and proposed reforms

This section focuses on

- i. Statistics on legal capacity restrictions;
- ii. Guardianship regimes affecting decision-making powers of adults with intellectual disabilities;
- iii. Regimes under which the legal capacity of adults with intellectual disabilities remains intact in theory;
- iv. Challenging appointments, decisions and review/removal of guardians.

20

The section does not give an in-depth analysis of guardianship-type procedures; appointment of support persons, legal guardians, conservators, curators, and tutors; diverse roles and activities of support persons, legal guardians, conservators, curators, and tutors. However, it maps *the role of legal guardians and support persons in decision-making processes*.

#### 2.1.1 Legal capacity restrictions in numbers

As noted, there is a distinct lack of quantitative research materials which indicate the number of people with intellectual disabilities whose legal capacity is restricted under measures such as guardianship or wards of court systems. The following materials were gathered from the little evidence that does exist.



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In 2012 in **Bulgaria**, according to a committee within the Bulgarian Ministry of Justice, there were 7,040 people placed under guardianship, out of which 6,249 were under plenary guardianship and 791 were under partial guardianship.<sup>63</sup>

According to KVPS, based on Statistics from Regional State Administrative Agency of Eastern Finland which is responsible for steering and development of local register offices, there were 64,100 wards in **Finland** in 2013. The majority of the wards, 62,305 people have full legal capacity. 1,749 people were living with restricted legal capacity and were placed under guardianship-type measures. Researchers do not have information about the remaining 56 people. Out of the 1,749 persons placed under guardianship, 625 people were placed under partial-type guardianship and 1,124 adults were declared incompetent and were placed under plenary-type guardianship.<sup>64</sup>

Estimates from **France** are gathered from the only available data collected in 2004. According to Governmental estimates there were approximately 700,000 people under protective measures in **France** in 2004.<sup>65</sup> Based on these statistics, 636,877 people were under the three types of legal capacity intervention: judicial safeguard, partial and plenary types of guardianship measures. Data shows that in 2004, 32,408 people were placed under the plenary guardianship-type tutorship and 33 009 people under the partial guardianship-type curatorship. In total, in 2004 in France 65,417 people were placed under guardianship-type measures.<sup>66</sup>

There were 57,944 people under guardianship in 2012 in **Hungary**. Out of this, 32,498 people were placed under plenary-type of guardianship, 22,826 under partial-type of guardianship and 2,620 under unknown type of guardianship.<sup>67</sup>

In **Ireland** in 2012 there were 2,344 people placed under wardship which is a plenary guardianship-type of system.<sup>68</sup>

All in all, it can be highlighted that the number of persons placed under guardianship-type measures greatly varies from country to country. Taking into account the population of the project countries,<sup>69</sup> the lowest number of people is placed under guardianship in **Finland** which has 32 persons under partial or plenary types of guardianship measures per 100,000 of the population. **Ireland** has 51 per 100,000 population under the wardship system. The next on this list is **Bulgaria** where this figure is

<sup>63</sup> Ministry of Justice working group on the implementation of Article 12 of CPRD in the national legislation: *Concept paper for amendments in the national legislation in order to comply with the standards of art.12 of the CRPD* adopted by Council of Ministers on 14 November 2012 (available in Bulgarian) <http://www.strategy.bg/Publications/View.aspx?lang=bg-BG&Id=138> last accessed 22 Sept 2014.

<sup>64</sup> Statistics are from Regional State Administrative Agency of Eastern Finland which is responsible for steering and development of local register offices

<sup>65</sup> Projet de loi portant réforme de la protection juridique des majeurs <http://www.senat.fr/rap/106-212/106-2126.html> last accessed 22 Sept 2014

<sup>66</sup> Ibid. Statistics from more recent years are not available. Unofficial sources within the judiciary estimate that in 2014, 800 000 to 1 million persons are under protective measures (Including judicial safeguard, partial or plenary guardianship).

<sup>67</sup> Based on the data provided by the National Office for the Judiciary on February 20, 2013

<sup>68</sup> Courts Service, Courts Service Annual Report 2012, 47 [http://www.courts.ie/Courts.ie/library3.nsf/\(WebFiles\)/87BE463114EF96FF80257BA20033953B/\\$FILE/Courts%20Service%20Annual%20Report%202012.pdf](http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/87BE463114EF96FF80257BA20033953B/$FILE/Courts%20Service%20Annual%20Report%202012.pdf) last accessed 2 July 2014

<sup>69</sup> Population of the project countries on 1 January 2014. Bulgaria: 7,245,677 people; Finland: 5,451,270 people; France: 65,856,609 people; Hungary: 9,879,000 people; Ireland: 4,604,029 people. See <http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&init=1&plugin=1&language=en&pcode=tps00001> last accessed 22 Sept 2014



97. Here the figure jumps to 586 and this high rate is linked to **Hungary**. The **French** figure is (according to 2004 figures) 967 if judicial safeguards are included, and 99 if only partial and plenary guardianship is counted.

### 2.1.2. Guardianship regimes affecting decision-making powers of adults with intellectual disabilities

All of the five project countries have a legal framework, which allows for the deprivation of legal capacity of adults with intellectual disabilities. A consequence of divesting adults with intellectual disabilities of their legal capacity is their placement under guardianship-type regimes. Although *these regimes are running under different names, they all remove the decision-making capacities of the person concerned and thus seriously affect several or all aspects of the life of the individual*.

Indeed, these regimes are called ‘plenary and partial guardianship’ in **Bulgaria**, ‘guardianship based on declaring the person concerned incompetent’ and partial guardianship in **Finland**,<sup>70</sup> ‘tutorship’ and ‘curatorship’ in **France**, ‘guardianship’ and ‘conservatorship’ in **Hungary**, and ‘wardship’ in **Ireland**.

The oldest legal guardianship-type regime operates in **Ireland** where provisions governing ‘wardship’ are contained in the Lunacy Regulation (Ireland) Act 1871.<sup>71</sup> The most recent legal framework is to be found in **Hungary** where the Act V. of 2013 on the Civil Code<sup>72</sup> has been in force since 15 March 2014. Provisions governing legal guardianship are rooted in the Guardianship Services Act (442/1999)<sup>73</sup> and in the Act on the Arrangement of Guardianship Services (575/2008) in **Finland**. In **France**, the Law 2007-308 of 5 March 2007<sup>74</sup> introduced reforms into the Civil Code regarding legal protection of adults, the provisions of which came into force on 1 January 2009. This law aimed at changing and clarifying the role and the missions of legal guardians from administering financial issues to taking on a social support role.

In **Bulgaria**, the substantive guardianship provisions are set out in the Law for Individuals and Family<sup>75</sup> and Chapter 11 of the Family Code<sup>76</sup> which was adopted in 2009.

<sup>70</sup> Incompetent person is defined in Guardianship Services Act’s Section 2 as a person under 18 years of age (minor) or a person who has attained the age of 18 years (adult) but who has been declared incompetent. For more information, see: Saarenpää, Ahti: Holhouksesta edunvalvontaan, Pohjois-Suomen tuomarikoulun julkaisuja (1-2/2000), 155-169

<sup>71</sup> Lunacy Regulation (Ireland) Act 1871 <http://www.irishstatutebook.ie/1871/en/act/pub/0022/print.html> last accessed 4 Sept 2014

<sup>72</sup> Promulgated on 26 February 2013. (Available in Hungarian) [http://www.complex.hu/kzldat/t1300005.htm/t1300005\\_0.htm](http://www.complex.hu/kzldat/t1300005.htm/t1300005_0.htm) last accessed 4 Sept 2014.

<sup>73</sup> Laki holhoustoimesta. (Unofficial English translation available at <http://www.finlex.fi/fi/laki/kaannokset/1999/en19990442.pdf> last accessed 4 Sept 2014)

<sup>74</sup> LOI n° 2007-308 du 5 mars 2007 portant réforme de la protection juridique des majeurs. (Available in French) <http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000430707&fastPos=1&fastReqId=291941796&categorieLien=id&oldAction=rechTexte> last accessed 4 Sept 2014

<sup>75</sup> Закон за лицата и семейството. (Available in Bulgarian) <http://lex.bg/bg/laws/ldoc/2121624577> last accessed 4 Sept 2014

<sup>76</sup> Семейен кодекс. (Available in Bulgarian) <http://www.lex.bg/bg/laws/ldoc/2135637484> last accessed 4 Sept 2014





The **Irish** wardship system completely removes the legal capacity of the individual where they are found to be ‘of unsound mind’ and incapable of managing his or her own affairs including his or her right to property and their right to decide where and with whom to live. It means that *Wardship is a regime of substituted decision-making*. There is *no form of partial guardianship* in Ireland. Order 67 of the Rules of the Superior Courts<sup>77</sup> outlines the procedural rules governing wardship applications and the administration of wardship.

According to the **Hungarian** guardianship system the legal capacity of an adult person can be limited fully or partially, thus the new terminology of the Civil Code refers to ‘Guardianship’ (guardianship with full limitation of legal capacity)<sup>78</sup> and ‘Conservatorship’ (guardianship with partial limitation of legal capacity).<sup>79</sup> The reasoning of the new Civil Code admits that the new regulation changes the name of the institution of ‘guardianship based on denial of legal capacity’ (plenary guardianship) due to its negative ‘implications’ to ‘guardianship with full limitation of legal capacity.’ People placed under ‘Conservatorship’ may make legal statements in all matters concerning which the court did limit their legal capacity. However, legal statements made by the persons concerned with respect to those matters regarding which the court did limit their legal capacity, are *valid only upon the conservator’s consent*.<sup>80</sup> Adults placed under ‘Guardianship’ are deemed legally incompetent, thus their legal statements shall be null and void and *their guardians make all decision on their behalf*. However, adults placed under ‘Guardianship’ may conclude ‘contracts of minor competence.’<sup>81</sup>

Under the **Finnish** Guardianship Services Act a person’s legal capacity can be limited in different ways, of which the most restrictive one is to declare a person ‘incompetent.’<sup>82</sup> A court may restrict the legal capacity of adults by allowing them to carry out particular legal acts or manage particular assets *only jointly with their guardians*. The other option is to restrict the legal capacity of the person concerned with the result that *s/he does not have the legal capacity to carry out particular legal acts* or the right to manage particular assets. If an adult is declared legally incompetent, it means that *s/he cannot self-administer his/her property or enter into contracts or other transactions*, unless otherwise provided elsewhere in the law.<sup>83</sup>

The **French** legislation differentiates between curatorship (partial guardianship) and tutorship (plenary guardianship). Adults placed under curatorship keep decision-making power in those areas of life where their legal capacity is not restricted. In those fields of life where the legal capacity of the person concerned is limited, *s/he can make legal statements only with the ‘assistance’ of the curator*. In other words, if the legal act of the adult under curatorship falls under those areas in which his/her legal capacity is restricted and the adult concerned does not want the curator to assist him/her, the legal act of the adult concerned will be null and void.<sup>84</sup> *Adults placed under tutorship are in a fully*

<sup>77</sup> Order 67 of the Rules of the Superior Courts <http://www.courts.ie/rules.nsf/8652fb610b0b37a980256db700399507/d82aae750369ba7d80256d2b0046b3a1?OpenDocument> last accessed 4 Sept 2014

<sup>78</sup> Section 2:21 of the Act V. of 2013 on the Civil Code

<sup>79</sup> Ibid Section 2:19

<sup>80</sup> Ibid Section 2:20(1)

<sup>81</sup> Cf. Section 2:22 of the Act V. of 2013 on the Civil Code

<sup>82</sup> Section 18 of Guardianship Services Act (HE 146/98) of 2 October 1998

<sup>83</sup> Ibid Section 23(1). Section 23(2) further clarifies that ‘Unless otherwise provided elsewhere in the law, a person who has been declared incompetent may self-decide on matters pertaining to his/her person, if he/she understands the significance of the matter’

<sup>84</sup> Articles 467 and 469 of the Civil Procedure Code (Code de procédure civile)



*representative status*, which means that the tutor has power to make decisions on behalf of the individual in almost all areas of life. However, the Civil Code identifies “strictly personal acts” which cannot be accomplished by anyone else than the person concerned.<sup>85</sup> This means that the person under tutorship shall not be assisted or represented regarding those acts which fall under “strictly personal acts.” The non-exhaustive list of “strictly personal acts” includes birth declaration, recognition of child, acts of parental authority on a child, declaration of choice or changing of the name of a child, and consent to adoption.

According to Anne Caron Déglise, most judges and legal professionals in France agree that

“legal [judicial] safeguard and curatorship are mostly in line with the UNCRPD, when applied well. They are supporting measures, while tutorship is a system of full guardianship (with no legal capacity of supported people).”<sup>86</sup>

Curators and tutors have to produce an ‘individual document of support’<sup>87</sup> together with the person with intellectual disabilities concerned. This document reflects, inter alia, on the needs of the person concerned, and the methods to improve the autonomy of the person concerned.

In **France**, a ‘family council’ might be set up once a person is placed under tutorship. A family council generally consist of 4-6 family members of the person concerned and they are charged with choosing the tutor. Authorisation coming from the family council is needed in order for the tutor to make decisions in certain situations such as issues related to property or heritage. Regarding the right to marry of a person placed under tutorship, the family council has to authorise the wedding of the person concerned.<sup>88</sup>

FEGAPEI reports that the French Ministry of Justice considers the French legal capacity legislation being based on Article 12 of the CRPD. According to the Ministry, *the problem does not lie within the legal framework; rather, efforts should turn to better implementation of the law and to changing the mentality of society.*

The **Bulgarian** legal framework provides for both plenary and partial guardianship. While plenary guardianship means that the adult’s legal capacity is entirely removed and the person is left with no legal powers, partial guardianship refers to limitation of legal capacity of the adult concerned. In other words it means that plenary guardianship is built on substituted decision-making of the guardian and people placed under partial guardianship may make legal actions only with the consent of the guardian.<sup>89</sup>

*All in all, substituted decision-making appears in all the five countries* and this is linked to ‘wardship’ in **Ireland**, ‘Guardianship’ in **Hungary**, ‘guardianship based on declaring the person concerned

<sup>85</sup> Article 458 of the French Civil Code

<sup>86</sup> French AJuPID report, 10. Anne Caron Deglise, former guardianship judge, and one of the authors of the 2007 law, defended this point of view during the implementation commission of UNCRPD at the CNCPH (National Consultative Committee of Disabled Persons), in June 2014

<sup>87</sup> L.471-7 alinea 3 (2°), D.311-0-2 du code de l’action sociale et des familles

<sup>88</sup> Articles 449 & 456 of the French Civil Code

<sup>89</sup> Articles 3-5 of the the Law for Individuals and Family





incompetent' in **Finland**, 'tutorship' in **France**, and 'plenary guardianship' in **Bulgaria**. Employing this type of decision-making is always the most restrictive way of denying a person's legal capacity. Hence, legal provisions in **Hungary, Finland and France** state that *this form of guardianship can only be used as a last resort option*.<sup>90</sup>

Comparing the guardianship legislation of the five countries, a unique tool can be identified in **France** with regard to tutorship and this is the '*family council*,' which has a monitoring, supervising role.<sup>91</sup> However, this tool is used less and less and is replaced by another tool established by the 2007 law: the 'subrogate tutor' who is also chosen by the judge to act as a countervailing power if needed.<sup>92</sup> The subrogated guardians may be a family member or a close associate and if not, a professional guardian. If the appointed guardian is chosen on the father's side, the judge must strive to choose the subrogate in the maternal branch for the sake of family balance. The mission of subrogate guardians is to monitor the acts carried out by the guardian and to notify the guardianship magistrate if anomalies or errors are remarked. For this, he is recipient of annual management reports and he must countersign them. He must replace the guardian when there is a conflict of interest for the execution of an Act, such as the settlement of a succession. Finally, the subrogate guardian must be informed by the appointed guardian prior to any serious act.

Another type of decision-making is in use in Hungary, Finland, France and Bulgaria and this is *linked to the consent of the conservator* in **Hungary**, *curator* in **France** and *guardian (or trustee)* in **Bulgaria**. Although this form of decision-making is often called 'joint decision-making' or 'co-decision-making' under partial guardianship, it is finally about the decision of the conservator, guardian, curator or trustee, since legal acts made by persons concerned cannot be valid without the approval of these persons. In **Finland** partial guardianship may mean that (1) the guardian has power to make the decisions alone in the scope of his/her task or (2) if restriction of legal capacity declares that in certain areas of life the guardian and the ward should make decisions together, then they have to make decisions jointly. However, Guardianship Services Act doesn't contain any provisions about situations where the guardian and the ward have different opinions concerning the ward's affairs. **Ireland's** legal framework does not provide for partial guardianship-type of measure.

<sup>90</sup> See: Section 2:21(3) of the Act V. of 2013 on the Hungarian Civil Code; Section 18(2) of Finnish Guardianship Services Act (HE 146/98) of 2 October 1998.; Article 440 of the French Civil Code.

<sup>91</sup> This mechanism is briefly described on page 4 of this Report.

<sup>92</sup> See art. 454 of Civil Code : "the subrogate curator or the subrogate tutor controls the acts made by the guardian (...) and shall inform the judge without delay if he found errors in the exercise of his mission. The subrogate curator or the subrogate tutor support or represent the person under protection when his interests are in opposition to those of the appointed curator or guardian or when one or the other cannot support him or act on his behalf due to the limitations of his mission. He is informed and consulted by the legal guardian before any serious act."



*In many cases, the roles of the guardians, curators, and tutors are considered as supportive, empowering and enabling towards adults with intellectual disabilities. However, these systems are inherently based on ‘joint decision-making’ or ‘substituted decision-making.’ Taking into consideration the authoritative interpretation of the CRPD Committee, these measures are not in line with Article 12 of the CRPD since:*

- *persons with intellectual disabilities do not enjoy legal capacity on an equal basis with others;*
- *enjoyment of legal capacity by persons with intellectual disabilities is not ensured in all aspects of life including the right to access to justice.*

### 2.1.3. Regimes under which the legal capacity of adults with intellectual disabilities remains intact in theory

Out of the five countries, measures without limiting a person’s legal capacity are available in 3 countries, namely in **Finland**, **France**, and in **Hungary**. In **Bulgaria** and **Ireland** legislative proposals have introduced alternatives to guardianship which respect the legal capacity of adults with intellectual disabilities.

In **Finland**, **France**, and in **Hungary** different measures are available in order to help adults with intellectual disabilities in exercising their legal capacity. These measures are the following:

- **In Finland:**
  - i. informal support arrangements without restricting the adult’s legal capacity and without appointing a guardian;
  - ii. appointing a guardian without limiting the adult’s legal capacity;
  - iii. continuing powers of attorney;
  - iv. authorization;
- **In France:**
  - i. judicial safeguard;
  - ii. MASP & MAJE (discussed below);
  - iii. ‘mandate for future protection’ (discussed below).
- **In Hungary:**
  - i. supported decision-making;
  - ii. professional supporters;
  - iii. preliminary legal statements.<sup>93</sup>

Legislative proposals have introduced the following alternatives to guardianship in **Bulgaria** and to wardship in **Ireland**:

- **In Bulgaria:**
  - i. supported decision-making;
  - ii. advance directives.

<sup>93</sup> The Hungarian term ‘előzetes jognyilatkozat’ is also translated by ‘prior legal statement.’ This report uses the notion of ‘preliminary legal statements’



- In Ireland:
  - i. Assisted decision-making;
  - ii. Co-Decision Making;
  - iii. Decision Making Representatives;
  - iv. Enduring Powers of Attorney;
  - v. Decision Making Orders by the High Court or the Circuit Court;
  - vi. Informal Decision Makers;

These practices will be elaborated upon below.

### Finland

The **Finnish** legal framework provides for the opportunity for *maintaining ‘informal support arrangements without restricting the adult’s legal capacity and without appointing a guardian.’* According to section 8 of the Guardianship Services Act:

“If an adult, owing to illness, disturbed mental faculties, diminished health or another comparable reason, is incapable of looking after his/her interests or taking care of personal or financial affairs in need of management, a court may appoint a guardian for him/her.”<sup>94</sup>

In the Finnish guardianship legislation

- i. a person’s intellectual disability never leads to an automatic procedure aiming to appoint a guardian;
- ii. a guardian can be appointed only in those situations when there are no other ways to help a person to take care of his/her financial or other affairs and he/she is incapable of looking after his/her interests and he/she has affairs in need of management; in other words it means that
- iii. appointing a guardian shall be a last resort option.

In practice this means that *even if a person has intellectual disabilities and he/she needs help in all areas of life. A guardian is not appointed if she/he doesn’t have affairs in need of management.* In addition to this, if the adult with intellectual disabilities does have affairs in need of management, but these affairs are already taken care of in some other way than through guardianship, there is no need to appoint a guardian.<sup>95</sup>

According to the Finnish Guardianship Services Act *there is a way to ‘appoint... a guardian for adults with intellectual disabilities without limiting their legal capacity.’* This option is based on the provision according to which

<sup>94</sup> Section 8(1) of the Finnish Guardianship Services Act

<sup>95</sup> The Finnish Supreme Court addressed this issue in the case of KKO:2009:7 in which it was alleged that a senior citizen was not able to take care of her financial affairs anymore by herself because of her diminished health status. The senior citizen argued that she did not need a guardian to be appointed for her because her affairs were taken care of by his son and the bank. The Supreme Court decided in favor of the senior citizen and did not appoint a guardian for her.



“The appointment of a guardian shall not disqualify the ward from self-administering his/her property or entering into transactions, unless otherwise provided elsewhere in the law.”<sup>96</sup>

In this case the role of the guardian is to provide the adult with intellectual disabilities with basic support and advice. However, the Guardianship Services Act contains provisions which give power to the guardian to make decisions against the will of the ward. Although the guardian *has to ask the ward’s opinion before making a decision, s/he is not obliged to act according to the ward’s will*. More precisely, the guardian has to inquire the opinion of the ward only in those situations, when ‘the matter is to be deemed important from the ward’s point of view and if the hearing can be arranged without considerable inconvenience.’<sup>97</sup> Moreover, “no hearing shall be necessary if the ward cannot understand the significance of the matter.”<sup>98</sup> These provisions allow guardians, for example, to sell the ward’s house without discussing it with him/her. These situations happen, for example in those cases when the ward is living in a care facility and not at the house in question.

The Finnish Government and the Parliamentary Ombudsman have already realised this problem and the Government highlighted the importance of the co-operation of the guardian with the ward especially in those situations where the ward’s legal capacity is not limited or is only partly restricted.<sup>99</sup> Similarly, the Parliamentary Ombudsman has also underlined the importance of the co-operation for example in the case of 4.5.2012 dnro 3943/4/11.

Other examples for *de facto* limitation of the right to legal capacity of adults with intellectual disabilities include:

- ‘If the ward has an account with a credit institution, the guardian shall notify the institution as to who has the right to withdraw funds from the account.’<sup>100</sup> This means that before the guardian gives this notification to the bank the ward can’t withdraw funds from his/her own bank account.
- A person for whom guardian has been appointed cannot be a member of the Board of Directors.<sup>101</sup>

According to the Finnish legislation a person has competence to make a ‘continuing powers of attorney’ if s/he has reached the age of majority (in Finland it is 18 years) and understands the meaning of continuing powers of attorney.<sup>102</sup> The objective of this instrument is to prepare for the future and for possible loss of functional capacity. In other words, this measure may be pronounced for ‘situations where a person has become incapable of looking after his/her interests or taking care of personal or financial affairs owing to illness, disturbed mental faculties, diminished health or another comparable reason.’<sup>103</sup>

Another alternative to guardianship under Finnish legislation is the so called ‘authorization,’ which is regulated in the Contracts Act. The main requirement for a person to be able to authorize another

<sup>96</sup> Section 14 of the Finnish Guardianship Services Act

<sup>97</sup> Ibid Section 43(1)

<sup>98</sup> Ibid Section 43(2)

<sup>99</sup> Government’s Proposal 146/1998

<sup>100</sup> Section 31(2) of the Finnish Guardianship Services Act

<sup>101</sup> Co-operatives Act (421/2013)

<sup>102</sup> Section 5 of the Act on Continuing Powers of Attorney

<sup>103</sup> Ibid Section 1



person is that s/he shall understand the meaning of this measure. Although oral authorization might be given, there are situations when written form is required e.g. selling a real estate. If the person concerned does not understand the meaning of the authorization any more (for example because of his/her health has declined), it still remains valid. In this case the only way to withdraw the authorization is to appoint a guardian for the person concerned in order for the guardian to be able to withdraw the authorization.

A different type of measure is called ‘negotiorum gestio’ according to which *individuals may make decisions on behalf of another person and voluntarily take action to take care of another person’s affairs*. This must be necessary in that situation and it can be used basically in situations where there is no time to wait for the appointment of the guardian. The recent Supreme Court case of KKO:2011:67 concerned an individual (‘A’) who received a brain injury in a traffic accident. There had been no guardian appointed to him during the pre-trial investigation. The question was whether A’s father had the right to ask - on behalf of his son - the prosecutor to bring charges for negligent bodily injury. A’s condition got suddenly worse and he could not take actions by himself. According to the Criminal Code of Finland the public prosecutor may bring charges for negligent bodily injury only if the injured party reports the offence for the bringing of charges. Finnish Supreme Court stated that A was unable to take care of his affairs in this matter because of his injuries. A’s father’s actions were necessary in this situation.

Supported decision-making also has been in discussion in Finland. Now there is a Government’s bill<sup>104</sup> concerning this in committee handling. The act is planned to concern social and health services especially.

29

## France

In **France**, there are three alternatives to ‘tutorship’ and ‘curatorship.’ These are

- i. ‘social and judicial support measure’ : MASP and MAJ<sup>105</sup>;
- ii. ‘judicial safeguard’<sup>106</sup> and
- iii. ‘mandate for future protection.’<sup>107</sup>

The reform of guardianship (law of 5 March 2007) has created a new mechanism of personalised support, divided in two subsequent supportive measures, for people with social difficulties.<sup>108</sup> It is a way for guardianship judges to avoid systematic use of the deprivation of legal capacity through more invasive measures of protection (curatorship, tutorship). This mechanism has a social character since it enables guardianship judges to appoint professional ‘trustees’ for those adults whose mental faculties are not altered and who experience difficulties regarding managing their social benefits, which may threaten their health and safety. It does not deprive the people concerned of any rights or

<sup>104</sup> Government’s Bill 108/2014

<sup>105</sup> MASP (‘Mesure d’accompagnement judiciaire.’), meaning personalized social support measure

MAJ (‘Mesure d’accompagnement judiciaire’), meaning judicial support measure

<sup>106</sup> ‘Sauvegarde de justice’

<sup>107</sup> Although this mandate applies once a person is deemed mentally incapable, and therefore a persons legal capacity is constrained when in effect, the advance planning mechanism can provide a means for their will and preference to be respected ‘Mandat de protection future’

<sup>108</sup> See art. L 271-1 to L 271-8 of Code of social Action and Families (<http://www.legifrance.gouv.fr/affichCode.do?idSectionTA=LEGISCTA000006157616&cidTexte=LEGITEXT000006074069>)



legal capacity and is designed to enable them to recover their ability to manage their budget independently.<sup>109</sup> Based on information gathered by FEGAPEI, it is assumed that this measure is not usually used by adults with intellectual disabilities. However, according to judges and staff courts,<sup>110</sup> it seems to be a possibility, especially for people with mild intellectual disabilities and psychosocial disabilities.<sup>111</sup>

The MASP (personalized social support measure) is the first part of the mechanism. It focuses on persons in great social difficulties without disability. The MASP is only open to adults who receive social benefits and whose health or safety is threatened by the difficulties they have to manage those resources.<sup>112</sup> It consists in a contract between the person and local authorities, in which the local authority offers to the beneficiary assistance to manage social benefits and individualized social support, through an appointed supportive association. If this fails (and the person does not achieve to manage his social benefits properly), then the local authority may ask the guardianship judge to pronounce a MAJ (judicial support measure). A MAJ is a social support organized in a legal framework to restore the autonomy of the person concerned in the management of his or her resources. In this case, a professional representative is appointed to receive the social benefits and manage them.

Although ‘judicial safeguard’ *aims not to limit the legal capacity of the person concerned, the judge may determine some acts which cannot be performed by the person concerned who can still exercise their civil rights*. In those acts (e.g. selling an estate), which are identified by the judge, the adult is represented by another person, mainly by relatives if possible. ‘Judicial safeguard’ can be ordered for adults

- who are temporarily in a situation of incapacity (e.g. coma), or
- ‘whose functional capacities are permanently affected (e.g. mental or physical capacities are preventing the person from expressing their will) and in need of immediate protection during the process of requesting to place the person under a more protective measure (tutorship or curatorship).’<sup>113</sup>

People placed under the measure of ‘judicial safeguard’ are denied to divorce by mutual consent or by acceptance.<sup>114</sup>

The measure of ‘mandate for future protection’<sup>115</sup> is an *advance planning document* that allows the person concerned to name one or more people to look after his/her well-being and manage his/her affairs, if the person concerned becomes incapable of doing so by himself/herself. This measure is restricted to persons who are not under ‘tutorship.’ Regarding adults with intellectual disabilities their parents are also allowed to produce this document in which they can choose the ‘tutor’ or the ‘curator’ and also the nature of the measure.<sup>116</sup> Although the measures discussed in this paragraph apply once a person is deemed incapable of making decisions by themselves – and hence his or her

<sup>109</sup> Article 495 of the French Civil Code. See also <http://www.unaf.fr/pf/spip.php?article3598> last accessed 4 Sept 2014

<sup>110</sup> See baseline study of France

<sup>111</sup> No data available

<sup>112</sup> It means that persons employed with proper salaries or retired in situations of over-indebtedness are excluded from its scope

<sup>113</sup> Articles 433-439 of the French Civil Code. See also <http://vosdroits.service-public.fr/particuliers/F2075.xhtml#N1016D> last accessed 4 Sept 2014

<sup>114</sup> See <http://vosdroits.service-public.fr/particuliers/F2075.xhtml#N1016D> last accessed 4 Sept 2014

<sup>115</sup> Articles 425 and 477 of the French Civil Code and ‘Circulaire CIV/01/09 du 9 février 2009’

<sup>116</sup> See <http://vosdroits.service-public.fr/particuliers/F16670.xhtml#N10172> last accessed on 4 Sept 2014



legal capacity is limited when in effect – the advance planning mechanism can provide a means for his or her will and preference to be respected at a future point in which they may need supportive interventions.

## Hungary

In **Hungary**, the Act V. of 2013 on the Civil Code has introduced three alternatives to ‘guardianship’ and ‘conservatorship.’ These are

- i. supported decision-making<sup>117</sup>;
- ii. professional supporters<sup>118</sup>;
- iii. preliminary legal statements.<sup>119</sup>

The measure of ‘supported decision-making’ is a tool which does not affect the legal capacity of adults with intellectual disabilities.<sup>120</sup> This legal instrument is available for

“adults in need of assistance due to the partial loss of his/her discretionary ability in certain matters.”<sup>121</sup>

The support person is appointed by the guardianship authority either based on the request of the person concerned ‘with a view to avoiding conservatorship invoking limited legal capacity,’ or on the basis of a court decision in a conservatorship or guardianship procedure.<sup>122</sup> The appointment of the support person shall happen in agreement with the person concerned.<sup>123</sup> A support person may be appointed for all areas of life or in respect of certain groups of affairs. However, *support person must not be appointed for those groups of affairs regarding which a conservator was appointed.*

Supported decision-making is a partnership based on confidentiality between the supported person and the support person. The support person may never act on behalf and in the name of the supported person but must do his/her best to

- establish a partnership based on confidentiality,
- to get to know the preferences and interests of the supported person,
- follow the life and decision-making situations of the supported person continuously and give the appropriate and tailor-made assistance based on their confidential relationship taking into account the abilities of the supported person and his/her demands concerning the amount of help.<sup>124</sup>

<sup>117</sup> Article 2:38 of the Act V of 2013 on the Civil Code; Act CLV of 2013 on Supported decision-making

<sup>118</sup> Articles 7-10 of the Act CLV of 2013 on Supported decision-making

<sup>119</sup> Articles 2:39 – 2:41 of the Act V of 2013 on the Civil Code

<sup>120</sup> Ibid Article 2:38(3)

<sup>121</sup> Ibid Article 2:38(1)

<sup>122</sup> Ibid Article 2:38(1)-(2)

<sup>123</sup> Ibid Article 2:38(2)

<sup>124</sup> Guide for the Rules of Procedure to be followed by guardianship authorities regarding supported decision-making, Summarized Rules of Procedure for guardianship authorities. (Without author, editor, date etc) Available in Hungarian at [http://www.macsgyoe.hu/downloads/szakmai\\_anyagok/tdeljarasrend.pdf](http://www.macsgyoe.hu/downloads/szakmai_anyagok/tdeljarasrend.pdf) last accessed 4 Sept 2014





Under the new Hungarian legislation ‘professional supporters’ can be appointed by guardianship authorities.

“Professional supporter shall be appointed, in the event of the person to be supported names no person who could be appointed as his/her supporter and s/he agrees to the appointment of a professional supporter.”<sup>125</sup>

*Professional guardians are entitled to be appointed as professional supporters and they may support 30-45 people in parallel.*<sup>126</sup>

The measure of ‘preliminary legal statements’ is an advance planning document which can be made by adults having full legal capacity for the case of losing their legal capacity either partially or fully. In preliminary legal statements, the person concerned may:

- “a) designate one or more persons whom s/he proposes to be appointed as his/her conservator or guardian;
- b) exclude one or more persons from the list of potential conservators and guardians; and
- c) instruct the conservator or the guardian regarding how to proceed with dealing with his/her specific personal and financial affairs.”<sup>127</sup>

If changes in the circumstances of the person, who has made preliminary legal statements result in a situation where instructions set out in the preliminary legal statements are likely to conflict with the interests of the person under conservatorship or guardianship, the court may be requested by the ward, the conservator, the guardian, the guardianship authority or the public prosecutor to abolish such instructions.<sup>128</sup>

32

## Bulgaria

Currently there are no alternatives to guardianship available for adults with intellectual disabilities in **Bulgaria**. The working group on the implementation of Article 12 of the CRPD which was set up by the Ministry of Justice and which was composed predominantly of representatives of non-governmental organizations prepared a concept paper<sup>129</sup> in August 2012. It was presented to the public at the end of September 2012,<sup>130</sup> and was adopted by the Bulgarian Council of Ministers on 14 November 2012. The concept paper envisages introduction of two alternatives to guardianship:

- i. supported decision-making;
- ii. advance directives.

<sup>125</sup> Act CLV of 2013 on Supported decision-making Article 7

<sup>126</sup> Ibid

<sup>127</sup> Section 2:39(2) of the the Act V of 2013 on the Civil Code

<sup>128</sup> Cf. ibid Section 2:41

<sup>129</sup> Bulgarian Centre for Non-profit Law, Concept paper for amendments in domestic legislation, related to the implementation of the standards of Art. 12 of the UN Convention for the Rights of Persons with Disabilities, (КОНЦЕПЦИЯ ЗА ПРОМЕНИ НА НАЦИОНАЛИНОТО ЗАКОНОДАТЕЛСТВО, СВЪРЗАНИ С ПРИЛАГАНЕТО НА СТАНДАРТИТЕ НА ЧЛ.12 ОТ КОНВЕНЦИЯТА НА ООН ЗА ПРАВАТА НА ХОРАТА СЪВРЕЖДАНИЯ), available in Bulgarian at: [http://www.bcnl.org/uploadfiles/documents/news\\_docs/2012/proekt\\_koncepcia.pdf](http://www.bcnl.org/uploadfiles/documents/news_docs/2012/proekt_koncepcia.pdf) last accessed 4 Sept 2014

<sup>130</sup> Bulgaria, Ministry of Justice, News, 27.09.2012, <https://mjs.bg/117/6/> last accessed 4 Sept 2014





However, there are no developments with regards to the legislative reform envisaged in the concept paper as of June 2014.

Along with the introduction of supported decision-making in the concept paper in 2012, pilot projects were also launched by the Global Initiative in Psychiatry, the National Organisation of Users of Mental Health Services, the Bulgarian Association of People with Intellectual Disabilities and the Bulgarian Centre for Not-for-Profit Law. The main objective of these projects is to promote supported decision-making.<sup>131</sup> In addition to this, cases were initiated and are currently pending before the Vidin Regional Court concerning two women with intellectual disabilities who are claiming that they receive sufficient support in the community in order to make independent decisions and they do not need to be placed under guardianship anymore.

### Ireland

Currently there is no measure in **Ireland** to support the exercise of legal capacity of adults with intellectual disabilities. However, the Assisted Decision-Making (Capacity) Bill 2013<sup>132</sup> was published on the 17 July 2013, and it purports to introduce a ‘support’ model of legal capacity and an automatic review of all current wards of court within 3 years of the commencement (coming into force) of the Act.<sup>133</sup> The model of assisted decision-making contained in the Bill takes the following forms:

- i. Assisted Decision Making;
- ii. Co-Decision Making;
- iii. Decision Making Representatives;
- iv. Enduring Powers of Attorney;
- v. Decision Making Orders by the High Court or the Circuit Court;
- vi. Informal Decision Makers.

33

*Assistance provided for in the Bill can only be accessed based on an application of a functional test of mental capacity, according to which:*

“... a person’s capacity shall be assessed on the basis of his or her ability to understand the nature and consequences of a decision to be made by him or her in the context of the available choices at the time the decision is made.”<sup>134</sup>

Under Section 3(2) the Bill requires a person to be deemed to lack mental capacity to make a decision where he or she is unable:

- “(a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or

<sup>131</sup> Information in Bulgarian available at:

[http://www.bcnl.org/uploadfiles/documents/legal%20workshop/presentation\\_nadya.pdf](http://www.bcnl.org/uploadfiles/documents/legal%20workshop/presentation_nadya.pdf) last accessed 4 Sept 2014

<sup>132</sup> Assisted Decision-Making (Capacity) Bill 2013. Available at:

<http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf> last accessed 4 Sept 2014

<sup>133</sup> Section 35(2) of 2013 Bill

<sup>134</sup> Ibid Section 3(1)



(d) to communicate his or her decision (whether by talking, writing, using sign language, assisted technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.”<sup>135</sup>

Commenting on different forms of assistance that are available under the Bill, Series points out that while Assisted Decision Making and Co-Decision Making ‘could more or less be construed as supported decision making,’ Decision Making Representatives and Informal Decision Makers ‘really cannot be.’<sup>136</sup>

‘Assisted Decision Making’ provides for formal agreements to be made by persons, including adults with intellectual disabilities, whereby *they may appoint a trusted person to act as their ‘decision-making assistant’ to assist them in making decisions regarding their personal welfare and/or property and affairs.* Decision-making authority remains with the appointer who will be actively assisted, typically by family members, relatives and carers, in accessing information, in understanding the information, in making and expressing decisions on matters specified in the agreement, and in implementing decisions made. The assistant must ascertain the will and preferences of the appointer and endeavour to ensure that the appointer’s decisions are implemented.

Under ‘Co-Decision Making’ a person appoints a ‘co-decision maker’ to *jointly make decisions with them where that person is determined to lack capacity to make that decision or those decisions alone.*<sup>137</sup> In other words it means, inter alia, that

“Where a relevant decision made by an appointer and a co-decision-maker requires a document to be signed in order to implement the decision, the document is void if the appointer and the co-decision-maker do not co-sign the document.”<sup>138</sup>

34

A co-decision maker must be a relative or friend of the individual<sup>139</sup> and must

- advise the appointer on relevant matters and decisions
- ascertain the will and preferences of the appointer on relevant matters and decisions
- assist the appointer to obtain relevant information
- assist the appointer to make and express a relevant decision, and
- ensure that the appointer’s relevant decisions are implemented.<sup>140</sup>

Where the court is unable to make a co-decision-making order or has made a declaration that a person lacks capacity even with the assistance of a co-decision-maker<sup>141</sup> the court may make orders either to make the decision or decisions itself (decision-making order) or to appoint a ‘decision-making representative’ to do so (decision-making representative order).<sup>142</sup> Where the court proposes

<sup>135</sup> Ibid Section 3(2)

<sup>136</sup> Lucy Series, *The Assisted Decision-Making (Capacity) Bill in Ireland - a bit of a mixed bag* (25 July 2013) The Small Places. Available at [http://thesmallplaces.blogspot.ie/2013/07/the-assisted-decision-making-capacity\\_25.html](http://thesmallplaces.blogspot.ie/2013/07/the-assisted-decision-making-capacity_25.html) last accessed 4 Sept 2014

<sup>137</sup> Section 16 of the 2013 Bill

<sup>138</sup> Ibid Section 21(2)

<sup>139</sup> Ibid Section 18(2)

<sup>140</sup> Ibid Section 21(3)

<sup>141</sup> Ibid Section 23(1)

<sup>142</sup> Ibid Section 23(2)



to appoint a decision-making representative and no suitable person is available or willing to act in this role, it may request the Public Guardian to nominate two or more persons from an established panel of decision-making representatives.<sup>143</sup> The court may appoint one of the nominees to be the decision-making representative for the relevant person.

According to Lucy Series:

“... unlike [co-decision makers] a [Decision Making Representative] can be a person who is effectively a stranger to the person (from a panel, appointed by the Public Guardian). There is nothing to place limits on how many people the [Decision Making Representative] may represent, nor how often they must meet with the person. There is nothing in the Bill which is as attentive to the quality of the relationship between a [Decision Making Representative] and the person they represent as there is for [Assisted Decision Making] and [Co-Decision Making].”<sup>144</sup>

In the case of both decision-making representatives and co-decision-makers there is the possibility of an individual’s will and preference being ignored or overruled where the Co-Decision Maker or Decision Making Representative believes that it is ‘unreasonable’. Flynn has argued that

“The roles of court appointed ‘decision-making representatives’ and ‘co-decision-makers’ in this new Bill could both potentially constitute substitute decision-making – especially where these individuals are not chosen by the person, and where they can either veto a decision the person wishes to make, or make a decision for that person which is not in accordance with her own will and preferences.”<sup>145</sup>

35

‘Enduring powers of attorney’ is an advance planning document which allows an individual (donor) to plan for a situation when s/he

“lacks or shortly may lack—

- (i) capacity to look after his or her personal welfare,
- (ii) capacity to manage his or her property and affairs, or
- (iii) both capacity to look after his or her personal welfare and capacity to manage his or her property and affairs.”<sup>146</sup>

Enduring powers of attorney are legal tools in which the donor may appoint someone that he or she trusts to take care of these affairs if the aforementioned situation arises. The donor retains the power to revoke the power of attorney at any time if s/he has the capacity to do so.<sup>147</sup>

<sup>143</sup> Ibid

<sup>144</sup> Lucy Series, *The Assisted Decision-Making (Capacity) Bill in Ireland - a bit of a mixed bag* (25 July 2013) The Small Places. Available at [http://thesmallplaces.blogspot.ie/2013/07/the-assisted-decision-making-capacity\\_25.html](http://thesmallplaces.blogspot.ie/2013/07/the-assisted-decision-making-capacity_25.html) last accessed 4 Sept 2014

<sup>145</sup> Eilíonóir Flynn, *Assisted Decision-Making (Capacity) Bill 2013 finally published* (17<sup>th</sup> July 2013) Human Rights in Ireland. Available at <http://humanrights.ie/mental-health-law-and-disability-law/assisted-decision-making-capacity-bill-2013-finally-published/> last accessed 4 Sept 2014

<sup>146</sup> Section 40(1)(a) of the Assisted Decision-Making (Capacity) Bill 2013

<sup>147</sup> Ibid Section 50(1)



Sections on ‘Informal decision making’<sup>148</sup> provides that a person referred to as an ‘informal decision maker’ may take or authorise the taking of action in respect of a relevant person on personal welfare, healthcare or treatment except in relation to non-therapeutic sterilisation, withdrawal of artificial life-sustaining treatment or the donation of an organ by the relevant person or closely connected matters.<sup>149</sup> Academic literature identifies this ‘intervention’ as substituted decision-making.<sup>150</sup>

## Conclusions

All in all, supported decision-making-type measures are either in force or planned to be introduced in **Bulgaria, Finland, Hungary, France** and in **Ireland**.

*Advance planning-type instruments are either in force or planned to be introduced in **all of the five countries** under different names: ‘continuing powers of attorney’ in **Finland**, ‘mandate for future protection’ in **France**, ‘preliminary legal statements’ in **Hungary**, ‘advance directives’ in **Bulgaria**, and ‘enduring powers of attorney’ in **Ireland**.*

A different type of measure is called ‘negotiorum gestio’ in **Finland** and ‘informal decision makers’ in **Ireland**. Both of these instruments concern *individuals who make decisions on behalf of another person and voluntarily take action to take care of another person’s affairs*.

Other types of measures than supported decision-making and advance planning-type documents include judicial safeguards in **France**, ‘appointment of a guardian without limiting the adult’s legal capacity’ and ‘authorization’ in **Finland**, ‘professional supporters’ in **Hungary**, ‘co-decision making,’ ‘decision making representatives,’ ‘decision making orders by the High Court or the Circuit Court,’ and ‘Informal Decision Makers’ in **Ireland**.

Although the aim of the alternatives to guardianship measures discussed above is to not to interfere with the right to legal capacity, in practice most of these instruments may hinder the equal enjoyment of the right to legal capacity by adults with intellectual disabilities. Thus, many of those measures which are entitled as alternatives to guardianship are not in line with Article 12 of the CRPD since

- persons with intellectual disabilities do not enjoy legal capacity on an equal basis with others;
- enjoyment of legal capacity by persons with intellectual disabilities is not ensured in all aspects of life including the right to access to justice;
- persons with intellectual disabilities are not provided with access to support in the

<sup>148</sup> Ibid Sections 53-54

<sup>149</sup> Cf. Speech by Minister for Justice, Equality & Defence at the Assisted Decision – Making (Capacity) Bill 2013: Consultation Symposium, Printworks Conference Centre, Dublin Castle, 25 September 2013. Available at: <http://www.justice.ie/en/JELR/Pages/SP13000341> last accessed 4 Sept 2014

<sup>150</sup> Series, *The Assisted Decision-Making (Capacity) Bill in Ireland - a bit of a mixed bag* (25 July 2013) The Small Places. Available at [http://thesmallplaces.blogspot.ie/2013/07/the-assisted-decision-making-capacity\\_25.html](http://thesmallplaces.blogspot.ie/2013/07/the-assisted-decision-making-capacity_25.html) last accessed 4 Sept 2014



- exercise of legal capacity in all areas of life including the right to access to justice; and
- these measures do not fully respect the person's rights, will and preferences.

#### 2.1.4. Challenging appointments, decisions, review/removal of guardians

Challenging appointments and decisions of guardians, review of guardians and removal of guardians are among the most important tools while adults with intellectual disabilities are living under the substituted decision-making (guardianship-type) paradigm and aiming to be part of the new, support paradigm.

Article 31 of the CRPD obliges States Parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the CRPD.<sup>151</sup> Furthermore,

“the information collected [...] shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention [CRPD] and to identify and address the barriers faced by persons with disabilities in exercising their rights.”<sup>152</sup>

Obligation of States Parties further extends to

- dissemination of statistics; and
- providing persons with disabilities and others with accessibility to these statistics.<sup>153</sup>

37

This section is based on research which was, inter alia, seeking for information regarding data on numbers of cases where individuals

- have successfully and unsuccessfully challenged the appointment of guardians;
- had guardians removed (comparing to failure of removal of guardians); and
- had legal capacity restored (comparing to failure of restoration of legal capacity).

#### Bulgaria

In **Bulgaria**, the legal framework regarding challenging appointments, decisions, review/removal of guardians can be described by highlighting that adults with intellectual disabilities placed under plenary guardianship are not entitled to appeal neither the appointment nor the decisions of their guardians. People with intellectual disabilities placed under partial guardianship may file such appeals but only with the consent of their guardian. In a 2014 decision, the Bulgarian Constitutional Court pointed out that:

“the lack of detailed legislative regulation of the legal regime concerning incapacitated adults leads not only to the limitation of those rights, the exercise of which carries a risk to the interests of incapacitated, third parties or the society, but also limits the exercising of

<sup>151</sup> Article 31(1) of the CRPD

<sup>152</sup> Ibid Article 31(2)

<sup>153</sup> Ibid Article 31(3)



unreasonably wide range of rights, including the constitutional ones. (...) The current legislative framework does not take into account the requirements of the CRPD – the restrictions of the rights of such persons to be proportionate to their condition, to apply for the shortest possible term and to be subject to regular review by an independent body.”<sup>154</sup>

Despite the old-fashioned legal framework the Sofia Regional Court delivered a judgment about changing the scope of a guardianship order from ‘plenary’ to ‘partial’ in 2013.<sup>155</sup> The case concerned an adult with intellectual disabilities and was initiated by the guardian. Researchers were informed about two pending cases before Vidin Regional Court. These cases concern two women with intellectual disability who want the court to restore their legal capacity. Although the complaints were filed by the women concerned they were signed by their guardians too. These cases were initiated on the basis of the argument according to which the women concerned receive sufficient assistance in the community which supports and compensates their disabilities and they are in a condition to make independent decisions.<sup>156</sup>

In Bulgaria, *statistics related to challenging appointments and decisions of guardians, review of guardians and removal of guardians are not publicly available*. A special request was sent to the Ministry of Justice by the researchers which, at the time of writing, has not been replied to (25 June 2014). Another request was sent to the Social Assistance Agency according to which researchers have to request this information from each and every of the 264 municipalities in Bulgaria since municipalities and mayors are the bodies responsible for appointment and removal of guardians under the Family Code.<sup>157</sup> The Agency itself does not maintain such database.

CIELA,<sup>158</sup> a Bulgarian data-base on legal decisions was also checked seeking for cases about challenging placement under guardianship. The search in CIELA was made by entering the keyword of ‘guardianship.’ After 2010 only four decisions about challenging/lifting guardianship were found where it can be presumed that the applicants were people with intellectual disabilities or their guardians on their behalf. Out of these four cases, in two cases it can be accepted that the applicants are for sure adults with intellectual disabilities or their guardians and in two cases it is not clear what exactly the disability of the people who applied for challenging guardianship was.<sup>159</sup> The rest of the decisions found in the data-base refer to people with psycho-social disabilities (mental health problems).

## Finland

<sup>154</sup> Decision 12/17.07.2014 issued by Constitutional Court on the case 10/2014. The decision is available in Bulgarian at: <http://constcourt.bg/acts> last accessed 4 Sept 2014

<sup>155</sup> Decision 18.02.2013 on civil case 4667/2012 issued by the Sofia Regional Court

<sup>156</sup> The information was received by the Bulgarian Association of the Persons with Intellectual Disabilities

<sup>157</sup> Bulgaria, Social Assistance Agency, Written reply 94CC/86, dated 27.05.2014, signed by the deputy-director of the Social Assistance Agency Yanita Manolova

<sup>158</sup> The decisions are published in the information system CIELA accessible only by having a password and username upon payment, available at: <http://web6.cielat.net/> last accessed 4 Sept 2014

<sup>159</sup> Bulgaria, Plovdiv Regional Court decision 1031, dated 10.06.2013., held on civil case 2374/2012 and Veliko Turnovo Regional Court decision 8, dated 25.02.2013, held on civil case 1366/2012. The first case decision lifted the guardianship and for the second – the published information is not sufficient so that the outcome can be clear.



In **Finland**, the appointment of a guardian is either based on a court decision or a decision made by the guardianship authority.<sup>160</sup> The decisions of a guardianship authority may be appealed by turning to the Administrative Court.<sup>161</sup> However, decisions on the appointment of a guardian and alterations to the tasks of the guardian are subject to appeal in a district court.

A court order concerning the appointment of a guardian or the restriction of someone's legal capacity may be appealed by the 'person whose interest is to be looked after' and the guardianship authority, as well as the guardian, parent, spouse, or other person close to the person concerned.<sup>162</sup> The decisions of a district court can be appealed in a court of appeal.

In 2013, district courts closed 6 of these requests in the whole country out of which

- in two cases actions were approved
- in one case action was dismissed
- in two cases actions were dismissed without considering merits, and
- in one case action was dropped.<sup>163</sup>

In Finland, available statistics are not well disaggregated. Although the *statistics gathered by researchers do not indicate how adults with intellectual disabilities managed to challenge their placement under guardianship*, the data presented here show that:

“In Finnish guardianship system it is quite difficult to successfully challenge decision concerning appointment of a guardian. Medical certificates have a big influence in this because they are still considered as primary evidence when considering the need of a guardian.”<sup>164</sup>

39

In 2012, the Court of appeals closed 41 cases concerning appointment of a guardian because of declined state of health. In 18 appeals the District Court's decision was not changed. In 7 appeals only the reasoning was changed but the conclusion stayed the same. The decision and reasoning were changed in 5 appeals because of the re-evaluation of the evidence. The decision and reasoning were changed in 2 appeals because of some other reasons which are not specified in the statistics. 2 appeals were dismissed without considering merits and 2 cases were returned to the District Court.<sup>165</sup>

## France

<sup>160</sup> Sections 10 and 12 of the of the Finnish Guardianship Services Act

<sup>161</sup> Ibid Section 87(1)

<sup>162</sup> Ibid Sections 80 and 72

<sup>163</sup> StatFin: Table Civil cases concluded by District Courts 2004-2013, method of instituting proceedings and conclusions [http://pxweb2.stat.fi/Dialog/varval.asp?ma=005\\_koikrs\\_tau\\_103\\_en&ti=Civil+cases+concluded+by+District+Courts+2004-2013%2C+method+of+instituting+proceedings+and+conclusions&path=../Database/StatFin/oik/koikrs/&lang=1&multilang=en](http://pxweb2.stat.fi/Dialog/varval.asp?ma=005_koikrs_tau_103_en&ti=Civil+cases+concluded+by+District+Courts+2004-2013%2C+method+of+instituting+proceedings+and+conclusions&path=../Database/StatFin/oik/koikrs/&lang=1&multilang=en) last accessed 4 Sept 2014

<sup>164</sup> Finnish AJuPID report. 16

<sup>165</sup> Taulukko: Hovioikeuksien toiminta 2009-2012. Available in Finnish at: [http://193.166.171.75/Dialog/varval.asp?ma=005\\_hovoi\\_kr\\_tau\\_102\\_fi&ti=Hovioikeuksien+toiminta+2009-2012&path=../Database/StatFin/oik/hovoi\\_kr/&lang=3&multilang=fi](http://193.166.171.75/Dialog/varval.asp?ma=005_hovoi_kr_tau_102_fi&ti=Hovioikeuksien+toiminta+2009-2012&path=../Database/StatFin/oik/hovoi_kr/&lang=3&multilang=fi) last accessed 4 Sept 2014



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In **France**, the court decision on the measure of curatorship or tutorship may be appealed by all of those people who are entitled to request the placement under curatorship or tutorship including the person with intellectual disabilities under either curatorship or tutorship.<sup>166</sup> However, if the judge refuses to place the person with intellectual disabilities under curatorship or tutorship, then only the person who initiated the procedure can make an appeal.<sup>167</sup> If the ‘family council’ makes a decision on behalf of the person placed under tutorship, members of the family council may contest the decision of the council.

The National Assembly is currently discussing and voting on a new law which aims to simplify the laws and procedures.<sup>168</sup> One of the aspects of this new law is that in certain situations (e.g. regarding persons with profound intellectual disabilities) the mandatory review of curatorship and tutorship may be extended up to 30 years.<sup>169</sup> This amendment would clearly contradict the rights of adults with intellectual disabilities under Article 12(4) of the CRPD which directs that States Parties must provide regular and independent review of any measures designed to assist in the exercise of legal capacity. An alliance of French disability NGOs highlighted this violation when the amendment was being debated in the National Assembly.<sup>170</sup>

In France relevant statistics are not available regarding challenging appointments and decisions of guardians, review of guardians and removal of guardians. According to informal sources, a system of contestation of guardianship-type measures and decisions taken by guardians is used, since every Court of Appeal regularly presides over such cases. As an example, in 2013, Paris’ Court of Appeal dealt with 700 contestation cases. It is unclear how many of these cases referred to persons with intellectual disabilities.

40

## Hungary

In **Hungary**, the court decision about placing a person with intellectual disabilities under guardianship or conservatorship is followed by a decision of the competent guardianship authority on the appointment of a guardian or a conservator. Adults with intellectual disabilities may challenge their placement under guardianship and conservatorship.<sup>171</sup> A person shall not be appointed as conservator or guardian if the person with intellectual disabilities placed under guardianship or conservatorship expresses an objection to the appointment of the proposed conservator or

<sup>166</sup> Articles 1239-1240 of the French Code of Civil Procedure

<sup>167</sup> A specific decree is dealing with this aspect of the 2007 amendments to the legal capacity legislation: Décret n° 2009-1628. Available only in French at:

[http://legifrance.gouv.fr/affichTexte.do?jsessionid=01380B84551D3C853E2D7D48935D4C3B.tpdjo05v\\_1?cidTexte=JORFTEXT000021527461&dateTexte=20140620](http://legifrance.gouv.fr/affichTexte.do?jsessionid=01380B84551D3C853E2D7D48935D4C3B.tpdjo05v_1?cidTexte=JORFTEXT000021527461&dateTexte=20140620) last accessed 4 Sept 2014

<sup>168</sup> See [http://www.assemblee-nationale.fr/14/dossiers/simplification\\_droit\\_justice\\_affaires\\_interieures.asp](http://www.assemblee-nationale.fr/14/dossiers/simplification_droit_justice_affaires_interieures.asp) last accessed 4 Sept 2014

<sup>169</sup> See <http://www.senat.fr/leg/pjl13-175.html> last accessed 4 Sept 2014

<sup>170</sup> According to the debat that took place in the implementation commission of UNCRPD in CNCPH (national consultative committee of persons with disabilities)

<sup>171</sup> Articles 49(1), 233(1), 306(1), and 312(3) of the Hungarian Code of Civil Procedure





guardian.<sup>172</sup> However, a professional guardian or conservator may be appointed even if the person with intellectual disabilities objects to it.<sup>173</sup>

Due to the legal provisions of the code of civil procedure<sup>174</sup> and the Act CXL of 2004 on the general rules of administrative proceedings and services,<sup>175</sup> persons with intellectual disabilities placed under either guardianship or conservatorship restricting legal capacity to initiate legal proceedings, do not have legal standing to challenge the appointment of the guardian or the conservator and are denied to challenge the decisions of the guardian or the conservator.

The Civil Code defines that mandatory review shall be done

- within five years from the date when the ruling becomes legally binding in the case of conservatorship, and
- within ten years from the date when the ruling becomes legally binding in the case of guardianship.<sup>176</sup>

In Hungary there are detailed data available regarding number of persons under conservatorship and guardianship collected by the Hungarian Central Statistical Office and the National Office for the Judiciary. However, *researchers were unable to find information on challenging appointment of guardians, removal of guardians and on restoration of legal capacity.*

## Ireland

In **Ireland** a person who has been made a Ward of Court cannot independently institute or defend legal proceedings. Regarding review of the measure in question,

“a wardship order is of indefinite duration. There is no systematic requirement that a person who has been made a Ward of Court be regularly visited or for periodic review of their welfare and general circumstances to be carried out.”<sup>177</sup>

Provisions of the Assisted Decision-Making (Capacity) Bill 2013<sup>178</sup> relating to Co-Decision Makers and Decision Making Representatives are reflected upon here due to the fact that both roles have the potential to amount to forms of substitute decision-making where the will and preference of the individual are not respected.

Once a co-decision-making order has been issued, the agreement can be revoked or varied only with the consent of the court. The relevant person may file such application.<sup>179</sup> For example, the court may revoke a co-decision-making order or vary the terms of an order if it is satisfied that ‘the

<sup>172</sup> Section 2:31(2) of the Hungarian Civil Code

<sup>173</sup> Article 134(7) of the Governmental Decree 149/1997 (IX.10)

<sup>174</sup> Article 49(1) of the of the Hungarian Code of Civil Procedure

<sup>175</sup> Article 15(6) of the Act CXL of 2004 on the general rules of administrative proceedings and services

<sup>176</sup> Section 2:29(1) of the Hungarian Civil Code

<sup>177</sup> Para 4.25 of the Consultation Paper on Vulnerable Adults and the Law: Capacity. Law Reform Commission (37) 2005

<sup>178</sup> Assisted Decision-Making (Capacity) Bill 2013. Available at

<http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf> last accessed 4 Sept 2014.

<sup>179</sup> Section 17(3) of the 2013 Bill



relationship between the relevant person and the co-decision-maker has broken down' to such an extent that making joint decisions is not possible or 'the relevant person is unable, unwilling or refusing to accept the assistance of the co-decision-maker'.<sup>180</sup>

Section 17(7) of the Assisted Decision-Making (Capacity) Bill 2013 provides for periodic review of a co-decision-making order not earlier than 3 months before and not later than 3 months after the first anniversary of the making of the order, and thereafter, at intervals such that there is no gap greater than 3 years between one review of the order and the next review of the order. However, the court can decline to carry out a review if it is satisfied that the review is unnecessary.<sup>181</sup>

The court may vary or discharge an order regarding Decision Making Representatives either of its own motion or upon application to it by authorized persons including the relevant person.<sup>182</sup>

Civil society organisations criticised the Bill because of lack of possibility to challenge choices of substitute decision-makers.<sup>183</sup> They point out that people should have a real ability to challenge decisions made under the Bill; especially

“people who are subject to more restrictive measures under the Bill must have a real ability to challenge the appointment of substitute decision-makers, as well as the decisions they make. This should include the right to independent advocacy for people subject to the Bill (including the immediate and full commencement of the Personal Advocacy Service provided for in the Citizens Information Act 2007), and learning from the valuable experience of the National Advocacy Service.”<sup>184</sup>

42

In Ireland, although statistics are available regarding the operation of wardship system, information related to the research questions are not available.

## Conclusions

*All in all, restriction of legal capacity and the placement under guardianship-type measure can be appealed by the adult with intellectual disabilities him/herself in three out of five countries, namely in **Finland**, **France** and in **Hungary**. This is the approach followed by the **Irish** Assisted Decision-Making (Capacity) Bill 2013.*

Under the **Bulgarian** plenary guardianship measure and the **Irish** wardship regime adults with intellectual disabilities are denied to challenge the court decision depriving them of their legal capacity and their placement under these total guardianship-type measures. **Bulgarian** legislation provides for a third option which is available only for those individuals who are placed under partial guardianship; under this option a person with intellectual disabilities may challenge the court

<sup>180</sup> Ibid Section 17(10)-(11)

<sup>181</sup> Ibid Section 17(8)

<sup>182</sup> Ibid Section 23(9)

<sup>183</sup> *Equality, Dignity and Human Rights - Does the Assisted Decision-Making (Capacity) Bill 2013 fulfil Ireland's human rights obligations under the Convention on the Rights of Persons with Disabilities?* (October 2013). p.5. Available at [http://www.nuigalway.ie/cdlp/documents/amendments\\_to\\_bill.pdf](http://www.nuigalway.ie/cdlp/documents/amendments_to_bill.pdf) last accessed 4 Sept 2014

<sup>184</sup> Ibid



decision restricting his/her legal capacity and his/her placement under partial guardianship only with the consent of his/her guardian.

Regarding information that was seeking for under the AJuPID project, it shall be emphasized that *comprehensive data on number of cases regarding challenging the appointment of guardians; outcome of these cases; and number of cases resulting in restoration of legal capacity or failure of restoration of legal capacity of people concerned do not exist in the five project countries.*

*As a result of denial or restriction of legal capacity to initiate legal proceedings regarding challenging placement under guardianship-type measures, appointments and decisions of guardians, review of guardians and removal of guardians:*

- *persons with intellectual disabilities do not enjoy legal capacity on an equal basis with others;*
- *enjoyment of legal capacity by persons with intellectual disabilities is not ensured in all aspects of life including the right to access to justice;*
- *these measures do not respect the person's rights, will and preferences;*
- *effective access to justice is not ensured for persons with intellectual disabilities.*

## 2.2 Adults with intellectual disabilities in the justice system

This Section of the report will focus specifically on access to justice for people with intellectual disabilities. In general, adults with intellectual disability face multiple barriers accessing the justice system. Exclusion extends beyond inaccessible courts and discriminatory laws, and includes barriers to a range of authorities, such as police, or complaint mechanisms.

A person's status with regards to guardianship is significant in determining his or her potential to access justice. On the one hand, guardianship systems pose a barrier to achieving justice because persons who are found to lack mental capacity (and thus placed under guardianship) are lawfully unable to initiate proceedings on their own behalf in most cases. As a result, several legal institutions closely related to fundamental rights are then compromised, including:

- marriage
- right to political participation, including the right to vote or stand for election
- healthcare interventions
- capacity to sue or be sued
- acting as witness in testamentary processes.

Guardianship – full or partial – necessarily restricts and/or denies the legal capacity of the relevant person and poses a significant barrier to accessing justice.



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On the other hand, guardians may be able to provide an avenue for achieving justice for adults with intellectual disability under existing law; for example, by initiating court proceedings, reporting abuse and exploitation, undertaking personal advocacy, and so on.

This ‘paradox of guardianship’ remains in place in all jurisdictions under consideration in this project (though Ireland has initiated moves to replace guardianship with a purported ‘support model’ of legal capacity). Like other jurisdictions around the world, Hungary, France, Finland and Ireland are grappling with the practical implications of Article 12 and 13 of the CRPD.

#### **a) Right to seek legal assistance and to directly instruct legal representation**

Opportunities for adults with intellectual disability to seek legal assistance and to directly instruct legal representation vary between countries. A significant factor impacting upon this right is, again, whether a person is placed under full or partial guardianship. Those under plenary guardianship are generally not permitted to access direct legal representation, even though their will and preference might be taken into account by substitute decision-makers. Those under partial guardianship have more varied rights to direct legal representation. Those with intellectual disabilities, more generally, who are not under any form of guardianship, will also face barriers to this right.

Adults with intellectual disability under plenary guardianship in countries that retain this form of denial of legal capacity, tend to not be able to directly instruct legal representation as the relevant person holds no legal standing. In **Bulgaria**, for example, those found to lack mental capacity under Article 4 of the Family Act are not allowed to act legally independently, which includes instructing legal representation. In **Hungary**, similar provisions under the new Civil Code provide that legal statements made by adults without legal capacity are null and void and their guardian shall proceed on their behalf.<sup>185</sup> Where a person is under plenary guardianship, courts have various requirements to consult his or her guardian who is typically required to act *in loco parentis*. However, such guardianship arrangements do not always result in the complete denial of the right to seek legal representation and instruct legal counsel. For example, in **Ireland** someone placed under wardship would have legal representation in the process described for Bulgaria and Hungary.

For those under partial guardianship in all countries, the provisions for legal representation differ. In all countries, the relevant person is restricted with regard to appointing legal representation without the consent and signature of the relevant person’s guardian. For example, in **Finland**, the Administrative Procedure Act Section 14 establishes that the right of a legally incompetent person to be heard shall be exercised by his/her guardian, custodian or other legal representative.<sup>186</sup> In **Bulgaria**, those under partial guardianship must have their guardians agree to legal representation, and consent by courts and other authorities is sought from guardians and not the relevant person.

There are exceptions to this general tendency across the jurisdictions. For example, in **Finland** persons deemed legally incompetent shall themselves exercise their right to be heard in a matter pertaining to income or assets in their possession, and shall themselves exercise their right to be heard in a matter pertaining to their person, *but only* if they are considered able to understand the

<sup>185</sup> Act V of 2013 on the Civil Code, Articles 2:21-22

<sup>186</sup> Administrative Procedure Act (Finland), Section 14.



significance of the matter. If guardianship is only partial and the task of the guardian does not cover the case concerned and the relevant person understands the significance of the case, the attorney/counsel discusses everything with the relevant person and he/she can direct legal instructions.<sup>187</sup> A further protection for those under guardianship exists in **Finland**, where there is provision for guardians to be heard in courts, where relevant, alongside persons under the guardianship order. However, the opinion of the relevant person shall prevail if he/she is deemed to have the mental capacity to understand the significance of the matter.<sup>188</sup>

Adults with intellectual disability who are not deemed to lack mental capacity, and those who are not under a guardianship order, undoubtedly face barriers to justice. In general, reports indicate that persons with intellectual disability face a lack of accessible information, support and assistance required for them to benefit from legal representation on an equal basis with others.<sup>189</sup>

However, some legal protections exist, which are both general (applying to all citizens) and specific (offering specific accommodations to adults with intellectual disability who may require support). For example, in **Finland**, when there is an adult as an applicant and there is no entry in the register of guardianship affairs, the authority/court basically draws the conclusion that the applicant has legal capacity.<sup>190</sup> In **France**, adults with intellectual disability who seek legal assistance hold a right to do so and to directly instruct legal representation regardless of whether the person is under guardianship.<sup>191</sup> In **France**, during his/her appearance before the judge, adults with intellectual disability have the right to be supported by a lawyer or by any person of their choice in civil cases (C.civ., art. 432, al.1er ), including a family member, a friend or a professional. The assistance of a lawyer is a right but not an obligation and the person must be informed of this right.<sup>192</sup> Similarly, in **Ireland** adults with intellectual disability are not automatically entitled to legal representation under the proposed *Assisted Decision-Making (Capacity) Bill 2013*.

45

In all countries a hearing before a judge can be cancelled by the judge if such a hearing is considered to pose a danger to the relevant person's health, as determined by a medical professional. There is some concern that this provision can exclude adults with intellectual disability from effective participation in a hearing and that meeting the judge is important and should not necessarily hinge on the expert advice of medical professionals, which then gives a great power to registered doctors who may have little knowledge of the person, and about the supports which would enable them to effectively participate in the hearing.

In **Ireland**, a statutory body called the 'Citizens Information Board' was created to support the provision of information, advice and advocacy on a broad range of public and social services.<sup>193</sup> The

<sup>187</sup> Code on Judicial Procedure (Finland) Chapter 15 Section 2.

<sup>188</sup> Administrative Procedure Act (Finland) Section 15, Paragraph 1. A similar provision exists in Code of Judicial Procedure (Finland) Chapter 12, Section 1a paragraph 1.

<sup>189</sup> See eg, Paul Swift, Kelley Johnson, Victoria Mason, Nour Shiyab, Susan Porter, 'What happens when people with learning disabilities need advice about the law?' University of Bristol, July 2013

<http://www.legalservicesconsumerpanel.org.uk/ourwork/vulnerableconsumers/Legal%20Advice%20Learning%20Disabilities%20Final%20Report.pdf> last accessed April 2014.

<sup>190</sup> Administrative Procedure Act and in Code of Judicial Procedure (Finland).

<sup>191</sup> Du code de procedure civile, Articles 1259-3, 479, 480, 484 & 493.

<sup>192</sup> C.pr.civ., Article 1214 al. 2.

<sup>193</sup> Citizens Information Act 2007. Available at <http://www.irishstatutebook.ie/2007/en/act/pub/0002/> last accessed 3 July 2014



legislation underpinning the body was intended to provide for a statutory advocacy service – the Personal Advocacy Service (PAS). Amongst the powers to be afforded to Personal Advocates, it was intended that they would be authorised to:

*assist, support and represent the person—*

*(i) to apply for and obtain a social service or services ...*

*(ii) if the personal advocate considers it appropriate to do so, to pursue any right of review, reference or appeal to a body other than a court if the application for such service or services is refused.<sup>194</sup>*

However, the PAS was never commenced. Instead, a National Advocacy Service (NAS) was created by the Citizens Information Board in January 2011. Unlike the PAS, the NAS does not have any statutory powers and states agencies and other services providers are not legally required to engage with it. NAS claims a particular remit for people with disabilities who are isolated from their community and services, have communication differences, are inappropriately accommodated, live in residential services, attend day services and have limited informal or natural supports.<sup>195</sup> Advocates under the NAS can serve as advocates for a person with a disability within the legal system also. For example, the result of the High Court case of *Legal Aid Board v. Judge Brady & Ors*<sup>196</sup> was the production of ‘Legal Aid Board Circular 2/2007’ which provided for a policy whereby the legal aid board would fund the use of ‘appropriate persons’ to support parents with disabilities when participating in child care proceedings. NAS advocates now serve this function.

46

Finally, for all countries considered in this study, it is noteworthy that legal aid mechanisms are available to adults with intellectual disability,<sup>197</sup> though it is unclear as to the extent to which guardianship status or mental capacity determinations impact upon this. Adults with disabilities in general, and those with intellectual disability in particular, are over-represented in statistics of socio-economic disadvantage.<sup>198</sup> Hence, access to justice mechanisms, such as legal aid schemes are relevant to the terms of this study. In **Hungary**, legal aid is formally available in proceedings around review of guardianship, revocation of guardianship, property, choice of where and with whom to live.<sup>199</sup> In **Ireland** more generally, adults with intellectual disability may apply for legal aid under the Civil Legal Aid Act 1995.<sup>200</sup> Eligibility is based on a means and merit test.

<sup>194</sup> Citizens Information Act 2007, Section 7D(1)(b)

<sup>195</sup> National Advocacy Service For People With Disabilities

[http://www.citizensinformationboard.ie/services/advocacy\\_services/](http://www.citizensinformationboard.ie/services/advocacy_services/) last accessed 3 July 2014.

<sup>196</sup> *Legal Aid Board v. Judge Brady & Ors* (2005/474 JR)

<sup>197</sup> See eg, in Bulgaria, the Legal Assistance Act,<sup>197</sup> which provides that socially vulnerable people have the right to free legal assistance, which includes persons with intellectual disability; in Hungary, Act LXXX of 2003 on Legal Aid

<sup>198</sup> See eg, World Health Organisation, ‘World Report on Disability,’ (author) 2011, 21 [http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf) last accessed 2 August 2014; see also E Emerson et al, ‘Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities’ (2006) 50 *Journal of Intellectual Disability Research* 862-873; E Emerson, C Hatton, ‘The socio-economic circumstances of children at risk of disability in Britain,’ (2007) 22 *Disability & Society* 563-580

<sup>199</sup> See eg, Act LXXX of 2003 on Legal Assistance, Articles 11, 12, 14, 15 and 16 [[http://net.jogtar.hu/jr/gen/hjegy\\_doc.cgi?docid=A0300080.TV](http://net.jogtar.hu/jr/gen/hjegy_doc.cgi?docid=A0300080.TV)]; Decree No. 56/2007 (XII. 22.) of the Ministry of Justice and Law Enforcement on the detailed rules for using legal assistance, [[http://www.complex.hu/jr/gen/hjegy\\_doc.cgi?docid=a0700056.irm](http://www.complex.hu/jr/gen/hjegy_doc.cgi?docid=a0700056.irm)]

<sup>200</sup> Civil Legal Aid Act 1995. Available at <http://www.irishstatutebook.ie/1995/en/act/pub/0032/index.html> last accessed 3 July 2014





Legal aid resources may be also available for persons with intellectual disability at non-government organisations. However, there remain few resources to assess how effectively persons with intellectual disability are making use of legal aid. Further, as the reports from each partner country demonstrate, a deprivation of legal capacity based on a guardianship ruling may preclude an individual accessing legal aid. Seemingly, guardians are also capable of accessing legal aid on behalf of the person, though little information is available. Finally, the combined reports indicate that legal professionals are not always given resources to work effectively with persons with intellectual disability. Difficulty remains where lawyers are not trained or supported to work with persons with intellectual disability.

Based against the human rights guidelines established at the beginning of this report, the following issues remain regarding the right to seek legal standing for persons with intellectual disability in the participating countries:

- persons with intellectual disabilities are not being supported to enjoy their legal capacity in regard to access to justice in some areas;
- support measures are in place, but often the best recourse to justice is through the guardian representative, a process which – under current law – does not respect the person’s rights, will and preferences; and
- some legal protections exist, including the use of legal aid mechanisms and personal advocacy services.

47

## b) Legal standing

In each country, the constitution provides for equal rights (in a formal sense) for all citizens, including persons with intellectual disability.<sup>201</sup> In practice, the legal standing of persons with intellectual disabilities to initiate a court or tribunal action depends upon whether they are deemed to have mental capacity, and whether they are under a guardianship arrangement.

In **Bulgaria**, for example, adults with intellectual disability who are under guardianship powers do not, in practice, hold legal standing to initiate legal proceedings. **Bulgaria’s** Civil Procedure Code, Article 28, indicates that persons under partial guardianship who are under the legal age (persons under the age of 18) can make a legal claim personally but only with the consent of their parents or guardians.<sup>202</sup> Those under plenary guardianship in **Bulgaria** have no right to legal standing to take a case on their own. In all countries that provide for plenary guardianship, those under such guardianship may not make valid legal statements. From a human rights perspective, this provision interferes with the autonomy, privacy and freedom of choice of such persons. In **Finland**, the Guardianship Services Act’s Section 72 establishes that a petition for the appointment of a guardian or the restriction of someone’s competency may be filed by the relevant person, as well as the guardian authority, the guardian, parent, spouse, child or other person close to the relevant person.

<sup>201</sup> See eg, Bulgaria, Constitution, Article 6, (enforced 6 February 2007)

<sup>202</sup> Bulgaria, Civil Procedure Code, (enforced 26 July 2013).





In **Hungary**, the legal status of the relevant person under supported decision-making and guardianship arrangements effects access to justice significantly. For example, the new Civil Code does not state separately that the guardian should, at a minimum, consider the will and preference of the ward. (Again, the CRPD indicates that will and preference should not be one consideration but should in fact *drive* decision-making by supporters of the relevant person).

In **France**, the person can initiate procedures and challenge courts decisions but never alone. She or he must be assisted or represented, depending on the nature of the guardianship measure. In the case of curatorship, it is not the guardian's role to initiate procedures or to defend the person in trial. The guardian, however, is required to support the person under his or her protection. In cases where the guardian does not support the person, the procedure may be considered as void.<sup>203</sup> In contrast, in the case of tutorship, the guardian initiates procedures and represents the person under his or her protection with authorisation of the guardianship judge. In cases concerning assets and property, the legal guardian can act independently. Regarding all other issues such as civic rights, privacy, and so on, the legal guardian must first get the approval of the guardianship judge or the Family Council, if there is one in place.<sup>204</sup> If a procedure to defend the rights of the person should be initiated and the guardian has not taken action, the guardianship judge must ask the guardian to do so. Otherwise the legal guardian can be made liable for negligence. Of course, if a person considers that he or she has been discriminated against, he or she can complain, as all citizens, to the Ombudsman.<sup>205</sup>

In **Ireland**, a number of mechanisms seek to provide for the legal standing of adults with intellectual disability, including those under the wardship system. With regard to initiating & defending legal proceedings, for example, Order 15, Rule 17 of the Rules of the Superior Courts, indicates that a "person of unsound mind" may sue as plaintiff by his wardship committee or next friend, and may defend by his committee or guardian appointed for that purpose. Similar practices exist in the lower courts. A ward of court can only take legal proceedings if the President of the High Court authorises the Committee to bring those proceedings on behalf of the ward. A ward of court may be sued. The High Court is capable of authorising legal representation of the ward in those proceedings. Any proposed settlement of proceedings to which a ward is party must be put before the President of the High Court for his approval.<sup>206</sup>

Under the Disability Act 2005 (**Ireland**) a person with an intellectual disability may make a complaint with regards to accessibility issues by him or herself or through the following persons:

- (a) a spouse, a parent or a relative of a person,
- (b) a guardian of that person or a person acting in loco parentis to that person,
- (c) a legal representative of that person, or
- (d) a personal advocate (as outlined above).

<sup>203</sup> Art. 468 and 467, Civil Code

<sup>204</sup> Art 475 of Civil Code

<sup>205</sup> LO (organic law) n° 2011-333

<sup>206</sup> Courts Service, *Wards of Court*. Available at

<http://www.courts.ie/offices.nsf/0/19111E254B2EF547802573D2006CCF26?OpenDocument> last accessed 7 July 2014



If, having done so, the person making the complaint disagrees with the determination of the internal inquiry, he or she may ask the Ombudsman to investigate the complaint. The Ombudsman may then make a finding that an action adversely affected the person and may recommend to the head of the public body concerned or to any other person concerned-

1. that the matter in relation to which the action was taken be further considered,
2. that measures or specified measures be taken to remedy, mitigate or alter the adverse affect of the action, or
3. that the reasons for taking the action be given to the Ombudsman,

Further, if the Ombudsman thinks fit to do so, he or she may request the head of the public body or that other person to notify him or her within a specified time of its or his or her response to the recommendation.<sup>207</sup>

There remain a number of barriers to people with intellectual disabilities enjoying legal standing on an equal basis with others:

- Good practices for assisting people to take part in legal proceedings is hampered where a person's legal standing is denied on the basis of a finding that a person lacks mental capacity – hence preventing their enjoyment of legal capacity on an equal basis with others;
- Failure to ensure the legal standing of persons with intellectual disability in law is a barrier to the right to access to justice – jurisdictions that allow a person to take part in legal proceedings regardless of decision-making ability provide stronger assurance of legal standing;
- There are examples of good practices with regards to the appointment of representatives by persons with intellectual disabilities which provide people with intellectual disabilities access to support in the exercise of legal capacity in the area of the right to access to justice;
- Some measures exist that respect the person's rights, will and preferences with regard to legal standing (notwithstanding the issues noted above);
- Measures can be taken to assist persons with intellectual disabilities to take part in proceedings as direct and indirect participants, though few jurisdictions contain them (discussed in the following sections).

### c) Right to be heard

The researchers considered the availability of legal mechanisms or practices in the justice system which require judges to personally meet with adults with intellectual disability who are the subject of a case. We asked if any regulations for this process exist.

In **Ireland** the National Federation of Voluntary Bodies reported that no such mechanism or practices currently exist in the Irish civil or administrative legal system.

<sup>207</sup> Ombudsman Act 1980, Section 6(3) as amended by Section 40 of the Disability Act 2005



In guardianship arrangements elsewhere, the relevant person reserves the right to be heard by courts with regard to the appointment in all countries considered.<sup>208</sup> For example, in **Finland**, Article 86 of the *Guardianship Services Act* directs that where a guardianship authority has been petitioned to appoint a guardian on the basis of section 12(1), the authority shall hear the relevant person face-to-face.<sup>209</sup> Similar provisions apply in District Courts in **Finland**.<sup>210</sup> Certain procedural accommodations are provided in **Finland**, such as technical equipment including video link (discussed in the next Section) to assist direct communication by the relevant person.

There is some evidence to suggest that the provisions for the right to be heard are not being realized in practice in **Finland**. For example, the right to be heard as a basic right has not been self-evident in courts concerning guardianship matters. KVPS reported that in the case of KKO:2009:68 the Supreme Court decided that when an adult has given consent to a local register office regarding the appointment of a guardian for him or her, then the District Court, which formalises the arrangement, does not have to reserve an opportunity to hear from the adult himself or herself. This ruling has raised strong criticism because it violated Section 73 of the Guardianship Services Act. As a result of the ruling, if the relevant person opposes appointment of a guardian to himself or herself, the court has to justify in its decision as to why the guardian has been appointed despite resistance from the relevant person. A later court ruling (KKO:2012:109) strengthened provision for the right to be heard in **Finland** but there remains little evidence to show whether or not this is translating into practice. On a more optimistic note, **Finnish** case law indicates that jurisprudence has shifted towards the person's procedural rights and legal safeguards, particularly related to hearing the wishes and preference of the person concerned.<sup>211</sup>

In **Bulgaria**, guardianship law directs that the relevant person, with regards to petitions to courts to restrict his or her legal capacity, should be questioned in person.<sup>212</sup> Under certain circumstances the relevant person may be brought to the court against his or her will, except in situations in which a person's health condition may be compromised.<sup>213</sup> This latter situation can be overcome under **Bulgarian** jurisdiction, where the judge visits the hospital or healthcare setting to see and speak with the adult. While this requirement does support the opportunity for the person to be heard by the judge, a personal visit by the judge *in lieu* of attendance at the court hearing does not ensure that the adult has the opportunity to respond to evidence nor does it ensure that the adult will have adequate opportunity to present evidence including calling witnesses.

Similarly, in **France**, a guardianship hearing in which the relevant person stands before the judge can be cancelled by the judge if it is considered a danger for the relevant person's health. The determination rests on the advice of a registered doctor.<sup>214</sup> FEGAPEI raised a concern that this provision is discriminatory 'because every person placed under protection should meet the judge'

<sup>208</sup> In Finland, see eg, Guardianship Services Act, Section 86

<sup>209</sup> Ibid

<sup>210</sup> According to Code of Judicial Procedure Chapter 8 Section 5 if a participant is to be reserved an opportunity to be heard in the non-contentious civil case, the District Court shall exhort him or her to submit a written statement in response to the application.

<sup>211</sup> See eg. KKO:2005:46 and KKO:2012:109

<sup>212</sup> Civil Procedure Code (Bulgaria) Article 337 (1) (enforced 26 July 2013) <http://lex.bg/laws/ldoc/2135558368> last accessed 2 August 2014

<sup>213</sup> Ibid

<sup>214</sup> C. pr.civ art 1219



and that this procedure ‘gives a great power to the registered doctor,’ who often has little knowledge of the relevant person and his or her family, friends, will and preference.

For the countries under consideration in this research, there are statutory grounds for dismissing the involvement of the relevant person with regards to a guardianship appointment; for example, if the petition for guardianship is at once rejected as ill-founded, or if the hearing is considered impossible because of the condition of the person to be heard, or if such involvement is considered to cause undue inconvenience to or compromise to the health of that person.

In **France**, the Civil Code states that the judge decides only after hearing the person.<sup>215</sup> The person can be supported by a lawyer or, with the approval of the judge, anyone else of the person’s choice. Nevertheless, on the basis on a medical advice<sup>216</sup>, the judge can decide that there is no need to hear the person, “if the hearing may damage the health of the person or, if the person is not able to express her will”.

In **Hungary**, persons under guardianship have procedural capacity to act only under certain circumstances, such as in some special civil court proceedings, having regard to the nature of the case (such as proceedings related to personal status like dissolution of marriage). Personal hearings are largely compulsory in these cases. However, the law provides discretionary power to the court to waive this obligation on the basis of “insurmountable obstacles”.<sup>217</sup>

The rules of the Act on Civil Procedure pertaining to most personal proceedings (divorce proceeding, conservatorship proceeding, for example) permit the court to dispense with an obligation to hear from people with intellectual disabilities and those under conservatorship with full restriction of legal capacity. This can have a profound effect on people’s personal lives. For example, the marriage of a person under conservatorship with full limitation of legal competency may be dissolved without the hearing of the relevant person (discussed shortly). In this case, the court is under no obligation to meet with the person on the basis that there is an obstacle deemed unavoidable in the opinion of the court. Hand in Hand has argued that persons with disability whose legal capacity is limited for any reason are excluded from participation in public administrative proceedings on this basis. As such, the ‘person cannot enforce his/her rights by operation of law and there is no need to hear him/her or obtain his/her consent in situations affecting his/her legal interests.’<sup>218</sup>

In **Hungary** a person’s guardianship status appears to provide an exception to typical statutory obligations for the relevant person to meet judges face-to-face. For example, Act V of 2013 on the Civil Code<sup>219</sup> regarding ‘enforcement of rights relating to personality’ states that

<sup>215</sup> See art. 432 of Civil Code

<sup>216</sup> See art 431 of Civil Code

<sup>217</sup> AJuPID project - ÉFOÉSZ’s comments: 08 July 2014 (Réka Danó dr.)

<sup>218</sup> Hand in Hand AJuPID report, 31. The Medical Advocacy Disability Centre (MDAC) is an international non-governmental organisation promoting and protecting the interests of persons living with a mental health problem or intellectual disability in Central and Eastern Europe. This analysis is a study prepared by the staff of MDAC (Benkó Boglárka, Fiala János and Gombos Gábor) on the rights of persons living with psycho-social disabilities in the light of the “UN Convention on the Rights of Persons with Disabilities”

<sup>219</sup> Promulgated on 26 February 2013



(2) Minors of limited legal capacity and persons of partially limited legal capacity shall be able to take action on their own for the protection of their personality rights. The personality rights of incompetent persons shall be protected by their legal representative.

Similar exceptions exist in statutory law regarding litigation. In divorce proceedings under Act III of 1952 on Civil Procedure, for example Article 85 (1) states that

At the first hearing of the divorce proceeding, the court hears the persons who appeared at the hearing. If either of the spouses is under *guardianship with a full limitation of legal competency* or if his/her place of abode is unknown or if there are other unavoidable obstacles to his/her personal attendance, *it is not obligatory to hear him/her in person.*<sup>220</sup>

The capacity to sue and be sued in **Hungarian** law is framed similarly. Act III of 1952 on Civil Procedure, for example, states:

Only such persons may be a party to the litigation (have the capacity to sue and be sued) who may have rights and be bound by obligations according to the rules of the civil law.

Article 48 states:

(1) The person who is party to a lawsuit, whether personally or via his/her agent, must be

- a) a person of full legal competency pursuant to the rules of the civil law,
- b) an adult of partially limited legal competency whose legal competency is not limited in respect of the subject matter of or the procedural acts realized during the lawsuit; or

...

(2) In the event the party has no legal capacity in lawsuits or if the party is a legal entity, the legal representative shall act on behalf of the party. The legal representative shall act on behalf of persons placed under conservatorship by the guardian authority without prejudice to legal competency as well, provided that the persons in question do not act personally on their own behalf. In the absence of a legal representative, the court shall appoint a guardian ad-litem for the party in question at the request of the counterparty (Article 74).<sup>221</sup>

Similar provisions exist in various sections of the Civil Code.<sup>222</sup> Regarding hearing and evidentiary proceedings, for example, Article 309 (1) states that '(t)he hearing of the defendant in person in the conservatorship proceeding may only be *dispensed with* in particularly justified cases, place of abode of the defendant is unknown or there are other unavoidable obstacles to his/her hearing.'

The right to be heard for people with intellectual disability is substantially strengthened where judges are required to meet people with intellectual disabilities involved in legal proceedings. Appointments of guardians and wardship orders typically contain provisions for face-to-face meetings with judges, though exceptions exist which potentially leave wide discretion to refuse such

<sup>220</sup> Code of Civil Procedure, Article 85(1)

<sup>221</sup> Ibid, Article 50(1)

<sup>222</sup> Ibid, Articles 50(1), 278, 306, 308, 85



meetings. One concern relates to the reliance on medical expertise to determine the appropriateness of inclusion. As such:

- persons with intellectual disabilities typically do not enjoy legal capacity on an equal basis with others with respect to being heard, although there are clear examples of positive steps taken to facilitate face-to-face meetings with judges, which constitute access to support in the exercise of legal capacity related to access to justice;
- effective access to justice is therefore not ensured for persons with intellectual disabilities with regards to the right to be heard;
- procedural accommodations and reasonable accommodations can assist but are not ensured for persons with intellectual disabilities;
- persons with intellectual disabilities are enabled in some cases to take part in proceedings as direct and indirect participants, but barriers remain, such as the discretionary power of medical professionals or the ease with which judges may be able to decide not to meet with the person.

#### d) Promotion of Direct Testimony

The researchers were concerned to identify any rules of evidence and procedure which enable people with disabilities to give direct testimony in court – and any regulations or reported cases involving the use of interpreters, or other communication supports, including augmented and alternative communication, facilitated communication, or total communication. The promotion of direct testimony differed between countries, where some provided procedural accommodations (discussed in the next section) while others did not appear to have any such provisions.

53

**Hungarian** law, under the Code of Civil Procedure, provides for assistance with legal proceedings to adults with a ‘hearing disability, deafblind people and persons with a speech defect.’<sup>223</sup> Yet such provisions appear to be applicable to others requiring support with communication to assist with direct testimony. The following example was provided by Hand in Hand:

*An example from the legal cases of the Legal Assistance Service of Hand in Hand Foundation:<sup>224</sup> A 22 year-old autistic woman had been sexually abused by her teacher for 8 years. The accused was acquitted in the second-instance court proceeding. The woman explained what had happened by means of “assisted communication.” The Medical Research Council (Egészségügyi Tudományos Tanács) established in the second-instance proceeding that assisted communication can be accepted as testimony.*

However, according to the same report ‘the effective legislation does not specify what should be taken into regard during the provision of information, thus the rights of persons with disabilities are infringed.’ Further, the same Code of Civil Procedure completely restricts persons from being heard as witnesses in court procedures for whom, due to their physical or mental disability, ‘relevant testimony cannot be expected.’<sup>225</sup> Act XIX of 1998 on penal procedure also expressly excludes

<sup>223</sup> Code of Civil Procedure, Article 184(2)

<sup>224</sup> Case No. 22\_260413 (Legal Aid Service of Hand in Hand Foundation)

<sup>225</sup> Act III of 1952 on Civil Procedure, Article 7





persons from hearing as witnesses, whose physical or mental condition would not enable them to take correct testimony. Act CXL of 2004 on administrative procedure and service also stipulates that those persons whose legal capacity is limited or who, due to his/her mental or other condition, are only able to restrictedly value the importance of making a legal statement, could only be authorized to make any statement if he/she wishes to do it and his/her legal representative agrees to it.<sup>226</sup> Hungarian laws with regard to restrictions on adults with intellectual disability providing direct testimony are typical to European laws more generally, and the provisions of support described above – while commendable – appear very much to be the exception to the rule.

In **Finland**, according to Judicial Procedure Act Chapter 17 Section 11 the following may not be admitted as evidence in a court, unless otherwise provided in an Act: a private written statement drawn up for the purpose of a pending or imminent trial, unless the court admits it for a special reason and an oral statement entered or otherwise stored in the record of a criminal investigation or another document. Although if the statement given in a pre-trial criminal investigation by a person who has not reached the age of 15 years or a person who is mentally incapacitated has been recorded on a video recording device or on a comparable video and audio recording, the statement may nonetheless be admitted as evidence in court if the defendant is provided with an opportunity to present questions to the person being heard. Section 21 contains provisions on the hearing of such a person as a witness or for a probative purpose. According to Section 21 a person who has not reached the age of fifteen years or who is mentally incapacitated may be heard as a witness or for probative purposes if the court deems this appropriate and if hearing him or her personally is of central significance to the clarification of the matter and hearing the person would probably not cause said person suffering or other harm that can injure him or her or his or her development. The court shall, as necessary, appoint a support person for the person to be heard and the provisions in chapter 2 of the Criminal Procedure Act (689/1997) on a support person to be appointed for a party apply to such person. The person to be heard shall be questioned by the court unless the court deems there to be particular reason to allow the parties to question the person as provided in section 33. The parties shall be reserved an opportunity to submit, through the court, questions to the person to be heard or, if the court deems this suitable, directly to the person to be heard. If necessary, the hearing may take place elsewhere than in the court room.

54

In **Bulgaria**, no provisions appeared to exist for promoting the direct testimony of adults with intellectual disability. In **France**, FEGAPEI reports that the presence of a lawyer is possible (art. 432 du code civil & art.1214 du code de procedure civile) yet no alternative communication or facilitated communication appeared to have been promoted for persons with intellectual disabilities under French law.<sup>227</sup>

In **Ireland** part 3 of the *Children Act 1997* refers to civil proceedings “concerning the welfare of a person who is of full age but who has a mental disability to such an extent that it is not reasonably possible for the person to live independently.”<sup>228</sup> The Act refers to such a person giving evidence via a live television link (addressed in the following section). In such cases the court may, of its own

<sup>226</sup> AJuPID project - ÉFOÉSZ's comments: 08 July 2014 (Réka Danó dr.)

<sup>227</sup> The law n°2005-102 does foresee accommodations such as sign language interpretation, Braille readers, accessibility of buildings, and so on.

<sup>228</sup> Children Act 1997, Section 20(b)





motion or on the application of a party to the proceedings, if satisfied that it is necessary having regard to the mental condition of the person, direct that any questions to be put to that person should be put through an intermediary.<sup>229</sup> These questions must be either in the words used by the questioner or in words that convey to the person, in a way that is appropriate to his or her mental condition, the meaning of the questions being asked.<sup>230</sup> This would presumably include supports for alternative forms of communication, however there is no recorded case law on this point.

A lack of promotion for direct communication of direct testimony raises similar human rights concerns to barriers to the right to be heard. For example:

- persons with intellectual disabilities are not able to enjoy legal capacity on an equal basis with others;
- enjoyment of legal capacity by persons with intellectual disabilities is not ensured regarding the right to access to justice where direct testimony is not promoted;
- persons with intellectual disabilities are not – in general – provided with access to support in the exercise of legal capacity regarding the right to access to justice;
- lack of direct testimony affects access to justice for persons with intellectual disabilities;
- there are very few procedural and age-appropriate accommodations for persons with intellectual disabilities regarding support to provide direct testimony;
- persons with intellectual disabilities are not enabled to take part in proceedings as direct and indirect participants, with some important exceptions which need to be supported and promoted.

55

#### e) Procedural Accommodations

The researchers were required to identify any procedural accommodations which enable adults with intellectual disability to participate in court proceedings – including the design of court rooms and proceedings, the use of less formal proceedings and settings (e.g. judges not wearing wigs and gowns or relaxing formal rules for court procedures) and the use of video testimony.

FEGAPEI reported no particular procedural accommodations in **France**. However, judges may arrange to meet and hear persons with disabilities outside the courtroom, eg. at their home, in a support facility, and in the hospital. According to judges interviewed, they frequently use this possibility.<sup>231</sup> Moreover, the law n°2005-102 for equal rights and opportunities, participation and citizenship of disabled persons, establishes general accommodations for disabled persons and aims to prevent discrimination. It promotes accessibility in all fields of social life and accommodations. Disability rights organizations and other representative NGOs may now file cases for a disabled person that has been discriminated against at work or in the process of applying for a job, with the written approval of the person him/herself (art. 24).<sup>232</sup> Since 2008, the organization around the Ombudsman has been

<sup>229</sup> Children Act 1997, Section 22(1)

<sup>230</sup> Children Act 1997, Section 22(2)

<sup>231</sup> See FEGAPEI baseline study.

<sup>232</sup> Art. L 122-45 Code of work



remodeled (previously “HALDE”). Being able to call on the French Ombudsman is a constitutional right since 2008. This can be done by the persons concerned, their relatives or a NGO.<sup>233</sup>

In **Ireland**, as noted, Section 21 of *Children Act 1997* provides for the giving of evidence by a person with a disability via live television link in civil proceedings concerning the welfare of a person who is of full age but who has a mental disability to such an extent that it is not reasonably possible for the person to live independently. Section 25(1) of the *Disability Act 2005* (Ireland) states that, subject to certain exceptions, a public body must ensure that its public buildings (including court buildings) are, as far as practicable, accessible to persons with disabilities. In the case of persons with intellectual disability, this could theoretically include signage, speech and language support, plain language guides, and so on. The 2005 Act also requires that where a service is provided by a public body, the head of the body shall:

- (a) where practicable and appropriate, ensure that the provision of access to the service by persons with and persons without disabilities is integrated,
- (b) where practicable and appropriate, provide for assistance, if requested, to persons with disabilities in accessing the service if the head is satisfied that such provision is necessary in order to ensure compliance with paragraph (a),
- and
- (c) where appropriate, ensure the availability of persons with appropriate expertise and skills to give advice to the body about the means of ensuring that the service provided by the body is accessible to persons with disabilities.<sup>234</sup>

Further, each head of a public body must authorise at least one of his or her officers to act as ‘access officers’ and provide or arrange for and co-ordinate the provision of assistance and guidance to persons with disabilities in accessing its services.<sup>235</sup> In civil proceedings, this would presumably include deconstructing legal jargon and court procedure. There is also provision for video link in courts, both with regard to wardship proceedings, but also outside the guardianship context, such as with regard to sexual offences cases. However, there is little evidence to indicate how commonly such provisions are used for adults.

In **Hungary**, Hand in Hand reported that no special legal regulation or practice exists in connection with procedural accommodations in courtrooms for adults with intellectual disability. However, some provisions exist for reasonable accommodations in general under Hungarian law. Act XXVI of 1998 on the Rights and Equal Opportunities of Persons with Disabilities defines the public services to which equal access must be ensured by the service providers. The Act regulates the scope of the obligations in specific detail, which includes all activities related to the powers of the state, including official, governmental and all other public administrative activities, as well as activities related to the administration of justice, and also the activities pursued by the Parliament, the bodies reporting to the Parliament, the Constitutional Court, the Commissioner for Fundamental Rights, the Public Prosecutor’s Office or the national defense and law enforcement bodies within their powers. Act

<sup>233</sup> Constitution, Art. 71-1

<sup>234</sup> Disability Act 2005 Section 26(1)

<sup>235</sup> Disability Act 2005 Section 26(2)



XXVI of 1998 on the rights and equal opportunities of person with disability defines *equal access* as follows:

- the access to the service is equal if all persons, with special regard to people impaired in functions such as movement, sight, hearing or mental and communicational functions, can apply for and use the service without difficulty, in a predictable, comprehensible and sensible manner, as independently as may be allowed by the conditions of the person in question;
- there is an equal opportunity to access the building, if it is accessible to all persons, with special regard to people impaired in functions such as movement, sight, hearing or mental and communicational functions, the parts of the building open to the public can be accessed and, in case of emergency, vacated with safety by all, and everyone can use the objects and equipment in the building according to the intended purpose thereof;
- the access to any information is equal if it is predictable, comprehensible and sensible to all persons, with special regard to people impaired in functions such as movement, sight, hearing or mental and communicational functions, and if all persons can access the information without difficulty.

The failure to remove physical barriers or ensure equal access to public services is regarded as direct negative discrimination in the legal practice of the courts and the Equal Treatment Authority (Egyenlő Bánásmód Hatóság) alike. There is little evidence available as to the successful application of such equality standards under **Hungarian** law with regard to access to justice for adults with intellectual disability.

57

All five countries in this study have enacted anti-discrimination legislation which prohibits discrimination on the basis of disability and requires the provision of reasonable accommodation to persons with disabilities in the sphere of employment as well as in the provision of goods and services. Non-discrimination legislation on the provision of services naturally encompasses services within the social welfare system (where guardianship is often located) as well as the justice system. However, none of the country reports identified any case law where the requirement to provide reasonable accommodation to persons with intellectual disabilities in the justice system (such as the provision of communication support to provide testimony, or the adaptation of court procedures) had been tested in the courts. Similarly, none of the country reports included any information on cases where reasonable accommodation had been provided to persons with intellectual disabilities to enhance their decision-making ability, as a less restrictive alternative to the appointment of a guardian or other substitute decision-maker. Nevertheless, existing anti-discrimination legislation, in particular the requirement to provide reasonable accommodation, has significant potential to enhance the exercise of legal capacity by persons with intellectual disabilities, as well as ensuring more effective access to justice.

In **Finland** the Non-Discrimination Act (21/2004) has been in force about ten years. In 2014, the Finnish government has sought to reform this act and others relating it, and is currently in committee stage.<sup>236</sup> The amendments that have been advanced seek to enlarge obligations for reasonable

<sup>236</sup> Government's Bill 19/2014



accommodations. In Non-Discrimination Act, which is still in force, this obligation concerns only persons commissioning work or arranging training. The bill enlarges the obligation to authorities and private service providers as well. Reasonable accommodations are understood as non-permanent ways to ensure that the services are available for a person with intellectual disabilities for example. In Finnish courts it is possible to change the place for a court session from a courtroom to another place, if needed. If the court has many courtrooms and others are for example in the first floor, it is possible to arrange a court room from there instead of using a court room in other floors, if they are more difficult to reach for a wheelchair-user. The accommodations required are usually investigated by the court before the first court session.

In **Finland**, as noted previously, the Guardianship Services Act provides, in certain circumstances, that the authority shall hear, in person, the relevant person.<sup>237</sup> A procedural accommodation is available in the form of technical equipment according to Guardianship Services Act's Section 86 paragraph 2. The use of technical equipment (such as telephone and video link) is possible if the distance between that person and the local register office are prohibitive, or for other reasons, such as if the person who should be heard is in a closed care facility. According to this section of the Guardianship Services Act it is also possible to use assistance of another local register office to make the personal hearing possible. These alternative ways to hear the relevant person were added to the Guardianship Services Act's Section 86 in 2011 in order to make local register offices more efficient.<sup>238</sup> The number of local register offices has been decreasing, which appears likely to continue.<sup>239</sup> This means that offices in smaller towns are vulnerable to being dismantled, and the distances to local register offices will become longer, making video link and other assistive communication technologies especially important.

58

In other court sessions (not simply regarding guardianship) there are also possibilities to use certain kinds of reasonable accommodations. According to Judicial Procedure Act Chapter 5 Section 15 d a preparatory session concerning civil cases may also be held by telephone or using another suitable means of communication, through which the persons present at the session have verbal contact with one another. These measures are undertaken with consideration to the nature and scope of the questions to be considered in the session, and a decision is made as to how appropriate they are to reach the goals of the preparation. The opinion of the parties is decisive in this process. If they give their permission, the means of communications are decided with a view to every party having a possibility to be heard and to participate in the discussions together. This section makes possible the use of telephone or video link in these situations. If during the session it becomes clear that the session cannot be held in this way, the court has to suspend the session and determine the session to be held in a court room.<sup>240</sup> Judicial Procedure Act Chapter 17 Section 34a sets out the potential to use a video conference or other appropriate technical means of communication, applicable if the court deems it suitable and the person to be heard cannot appear in person in the main hearing due

<sup>237</sup> Guardianship Services Act (Finland) Section 86. This requirement applies where a guardianship authority has been petitioned to appoint a guardian on the basis of section 12(1).

<sup>238</sup> Government proposal HE 203/2010 vp. s. 25

<sup>239</sup> Maistraattien toimipisteverkon supistaminen, Maistraattien ohjaus- ja kehittämisyksikkö, Itä-Suomen aluehallintoviraston julkaisuja 9/2014. Available in Finnish: <http://www.avi.fi/documents/10191/1308619/Maistraattien+toimipisteverkon+supistaminen/ab1c662a-1b3b-4214-a5c8-983dfb110e09> last accessed 2 August 2014

<sup>240</sup> Government's bill 32/2001 p. 43-44 (available only in Finnish)



to illness or another reason, and with a number of other provisos, including that the person to be heard has not reached the age of 15 years or he or she is considered to lack mental capacity. A party shall be reserved an opportunity to put questions to the person being heard. Telephone may not be used in the hearing if the procedural accommodations are necessary in order to protect the person to be heard or a person related to him or her, or the person to be heard is considered to lack mental capacity. According to Judicial Procedure Act Chapter 17 Section 21 it is also possible for the court or the person themselves to appoint a support person for main hearing to a person, who is considered to need it.

Procedural accommodations are not a common feature of the justice systems of the five countries though there are aspects in law and practice in some countries which provide support for people with intellectual disabilities to the right to access justice. As such a lack of procedural accommodations – which is evident for the most part in the countries – leads to the following:

- persons with intellectual disabilities do not enjoy legal capacity on an equal basis with others;
- enjoyment of legal capacity by persons with intellectual disabilities is not ensured in all aspects of life including the right to access to justice;
- persons with intellectual disabilities are not provided with access to support in the exercise of legal capacity in all areas of life including the right to access to justice;
- support measures cannot, therefore, respect the person's rights, will and preferences;
- effective access to justice is not ensured for persons with intellectual disabilities;
- procedural and age-appropriate accommodations are not ensured for persons with intellectual disabilities;
- reasonable accommodations are not ensured for persons with intellectual disabilities in the field of access to justice;
- persons with intellectual disabilities are therefore disabled from taking part in proceedings as direct and indirect participants.

59

#### f) Intermediaries and their Role

The researchers were concerned to identify any provisions in law which promote a role for intermediaries in communicating the views of adults with intellectual disabilities to the court and procedures or regulations regarding who can be an intermediary (parent, guardian, advocate, lawyer, litigation guardian/guardian ad litem, social worker, other professional, other family member or friend). They were also concerned to identify what the scope of intermediaries' role is; specifically, whether this role is simply to present the person's views to the court or to also suggest to the court what the possible outcome should be in the case, based on the individual's purported 'best interests' or other criteria.

In **France**, provisions allow for family to be heard by the judge in guardianship matters.<sup>241</sup> As noted, the relevant person can be assisted by a lawyer. The person's circle of acquaintances can also be consulted by the judge, if he or she decides to do so. However, there is no legal obligation to do as much. In **France**, FEGAPEI reports that there is no particular intermediaries of communication for

<sup>241</sup> Du code de procedure civile & Circulaire DACS n°CIV/01/09/C1 du 9 février 2009, Article 1220-4 [http://www.textes.justice.gouv.fr/art\\_pix/boj\\_20090001\\_0000\\_0036.pdf](http://www.textes.justice.gouv.fr/art_pix/boj_20090001_0000_0036.pdf) last accessed 2 August 2014.



adults with intellectual disability; no more that what exists in general to assist victims and alleged perpetrators of crime, and to assist people who want to initiate a procedure of justice (such as a lawyer, legal aid, associations of victims etc.).

In all countries except **Ireland**, country reports indicate that the only intermediaries available to adults with intellectual disability, in general, are guardians and/or the relevant person's families. Particular attention is paid in law to parents' rights in most countries. In **Bulgaria** for example, intermediaries of adults with intellectual disability under guardianship could be their parents or guardians.<sup>242</sup> This does not assure their involvement in legal proceedings related to the relevant person. In **Bulgaria**, NET Foundation reports 'judges decide whether to hear the guardian or the family members or both as witnesses to find out what the views of the person are to be placed under guardianship/whose guardianship is about to be lifted are.' In **France**, FEGAPEI reports that '(n)o particular procedural accommodations' for adults with intellectual disability appear to be in place with regard to intermediaries outside family and professional guardians. However, as noted, the effectiveness of guardians varies, and leaves considerable room for a non-uniform application of law. For example, the NET Foundation reported that in **Bulgaria** at least, '(t)he effectiveness of guardianship as an institution heavily depends on certain personal qualities of each guardian, such as their competence, diligence and conscientiousness.'

In **Finland**, neither the local registry office nor District Court has the obligation to hear parents, siblings or other informal supporters when appointing a guardian to an adult. The Finnish District Court has to reserve for a person's spouse an opportunity to be heard unless it is manifestly unnecessary. The Parliamentary Ombudsman of **Finland** has stated that the European Convention on Human Rights, and especially Article 8 and its obligation to honor one's family life, can create an obligation to hear person's family members when appointing a guardian to him/her.<sup>243</sup> According to the Parliamentary Ombudsman, authorities should choose the relevant procedural measure which honors the input of family and informal supporters.<sup>244</sup> In **Finland**, the local registry office is not obligated to hear anyone else than the person concerned but it usually does so. Family members are heard or are reserved an opportunity to be heard and are encouraged to submit a written statement in response to the application. If the person is living in a care facility, local registry office investigates the situation of the person by hearing the personnel of that facility. Family members are usually heard about the suitable guardian for the person concerned but also about the general situation in the person's life. It is always a case-by-case consideration in local register offices and in courts as to who is allowed to be heard. If the person concerned cannot be heard at all, the other people close to him/her can give information about this person and his/her situation in guardianship applications, including views on who would be appropriate for the task.

In Finnish courts more generally, family members can be appointed as support persons in main hearings according to Judicial Procedure Act Chapter 17 Section 21 paragraph 2. Of course it must be considered, if they themselves have a certain interest concerning the case so as to prevent a conflict

<sup>242</sup> Individuals and Family Act, Bulgaria (enforced 29 December 2002) <http://lex.bg/bg/laws/ldoc/2121624577> last accessed 2 August 2014.

<sup>243</sup> EOA 4.11.2002 dnro 1429/2/00

<sup>244</sup> Ibid





of interest. Support persons are used for example to help the communication between court, other parties and the person concerned.

In **Hungary** no special legal regulation or practice exists in connection with procedural accommodations in court rooms for persons with intellectual disabilities. Act XXVI of 1998 on the Rights and Equal Opportunities of Persons with Disabilities defines the public services to which equal access must be ensured by the service providers. The Act regulates the scope of the obligors in close detail. The scope of activities subject to the regulation includes all activities related to the powers of the state, including official, governmental and all other public administrative activities, as well as activities related to the administration of justice, and also the activities pursued by the Parliament, the bodies reporting to the Parliament, the Constitutional Court, the Commissioner for Fundamental Rights, the Public Prosecutor's Office or the national defense and law enforcement bodies within their powers. Act XXVI of 1998 on the rights and equal opportunities of person with disability defines *equal access* as follows:

- the access to the service is equal if all persons, with special regard to people impaired in functions such as movement, sight, hearing or mental and communicational functions, can apply for and use the service without difficulty, in a predictable, comprehensible and sensible manner, as independently as may be allowed by the conditions of the person in question;
- there is an equal opportunity to access the building, if it is accessible to all persons, with special regard to people impaired in functions such as movement, sight, hearing or mental and communicational functions, the parts of the building open to the public can be accessed and, in case of emergency, vacated with safety by all, and everyone can use the objects and equipment in the building according to the intended purpose thereof;
- the access to any information is equal if it is predictable, comprehensible and sensible to all persons, with special regard to people impaired in functions such as movement, sight, hearing or mental and communicational functions, and if all persons can access the information without difficulty.

61

The failure to remove physical barriers or ensure equal access to public services is regarded as direct negative discrimination in the legal practice of the courts and the Equal Treatment Authority (Egyenlő Bánásmód Hatóság) alike.

In **Ireland**, there are mechanisms for providing for intermediaries for adults with intellectual disability. As noted, under the *Children Protection Act* if the court is satisfied that it is necessary, having regarded to the mental condition of the person, the court will direct that any questions to be put to that person should be put through an intermediary.<sup>245</sup> Intermediaries can assist by making plain language 'interpretations' of court proceedings for the benefit of the relevant person, and or to provide assistance to communicate his or her response and contribution to such proceedings. In **Ireland** there is also a role for a 'next friend', as set out above in Section 2(b). However, NFVB reports that no clear guidance exists as to whether such persons are required to act solely based on the

<sup>245</sup> Children Act 1997 Section 22(1)





person's views or whether they may also make submissions based on their assessment of "best interests."<sup>246</sup>

Interestingly, no reference was made in any of the reports to speech and language therapists, or other professionals, being used to support communication in court.

The use of intermediaries can provide useful support for people with intellectual disability to access the right to justice. Without them – as is the case in almost all jurisdictions under consideration here – a number of rights are compromised, and as such:

- persons with intellectual disabilities cannot enjoy legal capacity on an equal basis with others;
- effective access to justice is not ensured for persons with intellectual disabilities;
- procedural and age-appropriate accommodations are not ensured for persons with intellectual disabilities;
- reasonable accommodations are not ensured for persons with intellectual disabilities in the field of access to justice;
- persons with intellectual disabilities are not enabled to take part in proceedings as direct and indirect participants;
- persons with intellectual disabilities are not provided with access to information and communication;
- the judiciary is not trained about their obligation to respect the rights of persons with intellectual disabilities.

<sup>246</sup> Irish AJuPID report, 22



### 3. Trainings for guardians and support persons

This section of the report focuses on existing or proposed elements of compulsory training for legal guardians and support persons on the rights of adults with intellectual disabilities and effective communication techniques.

In **Bulgaria** there are no compulsory trainings provided for guardians. Upon special request, the Social Assistance Agency replied that the Agency is not in a position to train guardians on a compulsory basis as they are independent persons with free will and cannot be obliged to participate in such training.<sup>247</sup> Researchers are not aware of any voluntary training offered for guardians in Bulgaria.

In **Finland** the legislation sets up certain requirements to be met by public guardians. These requirements include a completed appropriate higher education.<sup>248</sup> No further information is available on any training undertaken by or proposed for legal guardians and individuals providing support for persons with intellectual disabilities on the rights of persons with intellectual disabilities and effective communication techniques.

In **France** a publication on participation of persons, inter alia, with intellectual disabilities in the implementation of the measures of tutorship and curatorship was published in 2012.<sup>249</sup> This document provides professional guardians with good examples and recommendations on:

- participation of persons with intellectual disabilities in tutorship and curatorship measures
- involvement of the family
- use of an 'individual document of support'
- functioning of services of professional guardians.

In order to become a legal guardian, a national certificate of skills has to be obtained. The certificate can only be obtained if the following training modules are completed:

- A theoretical training of 300 hours for tutorship and curatorship and 180 hours for legal assistance, and
- A practical training of 350 hours.

These trainings' aim is to assist legal guardians to acquire social and administrative competences, as well as knowledge on the legal framework and rights of persons under tutorship and curatorship.<sup>250</sup> Only certified training centres are allowed to conduct such trainings.

<sup>247</sup> Bulgaria, Social Assistance Agency, Written reply 94CC/86, dated 27.05.2014, signed by the deputy-director of the Social Assistance Agency Yanita Manolova

<sup>248</sup> Act on Organization of Guardianship Services (laki holhoustoimen edunvalvontapalveluiden järjestämisestä, 575/2008) and Section 1(a) of the Ministry of Justice decree on State Legal Aid Offices, Section 4.

<sup>249</sup> Agence nationale de l'évaluation et de la qualité des établissements et services sociaux et médico-sociaux (Anesm): Participation des personnes protégées dans la mise en œuvre des mesures de protection. Recommandations de bonnes pratiques professionnelles. 2012. last accessed 4 Sept 2014



In **Hungary**, training material entitled ‘Training program for the retraining of public guardians to be professional supporters’ was published in 2014.<sup>251</sup> The training is built on this publication is compulsory for public guardians. The modules of the training document focus on:

- legal studies;
- information on persons concerned;
- basics of communication.

The objective of the ‘legal studies’ module is that participants shall become familiar with the legal capacity related provisions of the new Civil Code and legal issues related to the activities of public guardians and conservators and professional supporters. The aim of the module entitled ‘information on persons concerned’ is to provide participants with knowledge on and promote a shift in attitudes towards clients. The purpose of the ‘basics of communication’ module is to improve participants’ ability to communicate, connect and effectively cooperate with clients by means of various skills development exercises.

In 2011 the Hungarian Association for Persons with Intellectual Disabilities (ÉFOÉSZ) published a document on a model experiment programme on supported decision-making.<sup>252</sup> ÉFOÉSZ participates in the ‘Pathways II’ project coordinated by Inclusion Europe. One of the objectives of the project is to disseminate easy-to-understand communication.<sup>253</sup> A publication entitled ‘Information for all – European standards for making information easy to read and understand’ was published under the project.<sup>254</sup> Furthermore, the Hand in Hand<sup>255</sup> foundation developed training on easy-to-understand communication.<sup>256</sup>

In **Ireland** no information is available on any training undertaken by the General Solicitor or staff of the Office of Wards of Court. In 2012, Advocates of the National Advocacy Service (NAS)<sup>257</sup> participated in training which includes Mental Health Training, Assistive Technology, Social Policy, Autism Awareness, Self-Care, Presentation Skills, Identification of Need Children & Families, Manual

<sup>250</sup> See Circular, DACS n° CIV/01/09/C1, p 16-17 & to see the content of the training: [http://www.tutelle-curatelle.com/formation\\_curateur\\_tuteur.htm#formations](http://www.tutelle-curatelle.com/formation_curateur_tuteur.htm#formations) last accessed 4 Sept 2014

<sup>251</sup> Danó Réka, Gazsi Adrienn, Mattenheim Gréta, Dósa Piroska: Képzési tananyag. Az új Polgári Törvénykönyv cselekvőképességi szabályainak alkalmazása. Képzési program hivatásos gondnokok hivatásos támogatóvá történő átképzéséhez c. 22 órás képzéshez. [Réka Danó, Adrienn Gazsi, Gréta Mattenheim, Piroska Dósa: Training material – Application of the rules governing legal capacity in the new Civil Code prepared for the 22 hours training entitled ‘Training program for the retraining of public guardians to be professional supporters.’ 2014 EMMI TAMOP 541.] Available in Hungarian at [http://www.macsgyoe.hu/downloads/szakmai\\_anyagok/tdkepzes.pdf](http://www.macsgyoe.hu/downloads/szakmai_anyagok/tdkepzes.pdf) last accessed 4 Sept 2014

<sup>252</sup> Horváthné Somogyi Ildikó, Danó Réka, Tóth Szilvia: Supported decision-making – Experience gathered in the model experiment program of ÉFOÉSZ (ÉFOÉSZ, 2011)

<sup>253</sup> For the Hungarian site see [www.life-long-learning.eu](http://www.life-long-learning.eu) last accessed 4 Sept 2014

<sup>254</sup> For the Hungarian version see [http://www.inclusion-europe.org/pathways2/images/Information\\_for\\_all-HU.pdf](http://www.inclusion-europe.org/pathways2/images/Information_for_all-HU.pdf) last accessed 4 Sept 2014

<sup>255</sup> ‘Kézenfogva alapítvány.’

<sup>256</sup> The training is entitled ‘Könnyen Érthető Kommunikáció’ (Making communication easy to understand) [Kézenfogva Alapítvány, T-05-153/2009]

<sup>257</sup> The National Advocacy Service for People with Disabilities (NAS) was launched on 31 2011. The National Advocacy Service for People with Disabilities provides an independent, confidential and free, representative advocacy service that works exclusively for the person using the service and adheres to the highest professional standards. NAS works to ensure that when life decisions are made, due consideration is given to the will and preference of people with disabilities and that their rights are safeguarded. [http://www.citizensinformationboard.ie/services/advocacy\\_services/](http://www.citizensinformationboard.ie/services/advocacy_services/) last accessed 4 Sept 2014.



Handling, and Litigation.<sup>258</sup> In their 2012 Annual Report, the National Advocacy Service recognizes that

There is an identified need to develop a set of core training modules that all current and new NAS staff should complete, to ensure standardisation and quality practice. Such 'core' training would address the 'clarity of purpose' that is required in order for the national team to have a common understanding of the role, boundaries and limitations of the service. Planning for this training will take place in 2013.<sup>259</sup>

All in all, *compulsory trainings for legal guardians on the rights of persons with intellectual disabilities and effective communication techniques are not available in three out five project countries, namely in Bulgaria, Finland and Ireland.* However, this does not mean that in these countries there is not any training provided for legal guardians. Unfortunately, there is no information available from these countries regarding proposed elements of training events focusing on the rights of persons with intellectual disabilities and effective communication techniques. In **Hungary**, special training has to be completed by public guardians where they can improve their knowledge, not only on the rights of persons with intellectual disabilities but on effective communication techniques as well.

*Lack of compulsory or even non-compulsory trainings offered for legal guardians and support persons on the rights of persons with intellectual disabilities and effective communication techniques leads to the following:*

- *persons with intellectual disabilities do not enjoy legal capacity on an equal basis with others;*
- *enjoyment of legal capacity by persons with intellectual disabilities is not ensured in all aspects of life including the right to access to justice;*
- *persons with intellectual disabilities are not provided with access to support in the exercise of legal capacity in all areas of life including the right to access to justice;*
- *support measures do not respect the person's rights, will and preferences;*
- *effective access to justice is not ensured for persons with intellectual disabilities;*
- *persons with intellectual disabilities are not enabled to take part in proceedings as direct and indirect participants;*
- *persons with intellectual disabilities are not provided with access to information and communication.*

65

<sup>258</sup> Citizens Information Board - National Advocacy Service for People with Disabilities, *Annual Report 2012*. 23. Available at [http://www.citizensinformationboard.ie/publications/advocacy/NAS\\_AnnualReport\\_2012.pdf](http://www.citizensinformationboard.ie/publications/advocacy/NAS_AnnualReport_2012.pdf) last accessed 4 Sept 2014

<sup>259</sup> Ibid 24



## 4. Trainings for officials in the justice system

This section of the report focuses on existing or proposed elements of compulsory training for officials in the justice system (lawyers, judges, clerks, notaries, etc.) on the rights of persons with intellectual disabilities and effective communication techniques.

In **Bulgaria**, the Ministry of Justice was approached in order to get relevant information; however reply was not provided for researchers until 25 June 2014.

In **Finland**, although judges are provided with trainings on how to interpret legal provisions and human rights are reflected on during these events, there is no compulsory training for officials in the justice system focusing especially on the rights of persons with intellectual disabilities and effective communication techniques.

In **France**, no information is available regarding the existence or proposed elements of any compulsory training for officials in the justice system reflecting on the rights of persons with intellectual disabilities and effective communication techniques.<sup>260</sup>

In **Hungary**, a special training entitled ‘Building bridges: human rights in judicial law enforcement and communication’ was organized for judges and other court staff by the Hungarian Judicial Academy in 2008. This event focused on child rights, roma rights and disability rights and legal capacity related issues and need for special communication techniques were also touched upon. Trainers found that situational exercises and debates were very fruitful elements of the training.<sup>261</sup> Trainings were also offered for judges and other court staff on ‘the role of prejudices, stereotypes and discrimination in judicial decision-making’ in 2007-2008; ‘the social correlations of judicial decision-making’ in 2008; ‘the independence of judges’ in 2009; ‘racially motivated crime’ in 2012.<sup>262</sup>

Judges and other court staff who came to participate in the training events found both the topics and the content of the programs useful. They mentioned that they would be happy to participate in similar events in the future as well. The same demand was formulated at the conference organized by the Hungarian Commissioner for Fundamental Rights in March 2013 at the Hungarian Judicial Academy on the reform of trainings of judges and the judicial staff. This event was attended by members of the staff in charge of education at the Supreme Court, courts of appeal, superior courts and members of the National Judicial Council.<sup>263</sup>

In **Ireland**, no information is available regarding the existence of any such professional training or the likelihood of such training taking place in the future.

<sup>260</sup> The lifelong learning catalogue of the national school of magistrature (ENM) shows that there is no official training about persons with intellectual disabilities (neither in terms of rights nor in terms of communication techniques). See <https://formation.enm.justice.fr/> last accessed 4 September 2014

<sup>261</sup> See <http://www.jogiforum.hu/hirek/17390> last accessed 4 Sept 2014

<sup>262</sup> Report of the Commissioner for Fundamental Rights in case No. AJB-1199/2013 (Related cases: AJB-1197/2013; AJB-1198/2013.; AJB-1200/2013.; AJB-1201/2013; AJB-1202/2013). 2013. 48-49. Available in Hungarian at [www.ajbh.hu/documents/10180/111959/201301199.doc](http://www.ajbh.hu/documents/10180/111959/201301199.doc) last accessed 4 Sept 2014

<sup>263</sup> Ibid 49



All in all, compulsory trainings for officials in the justice system (excluding guardians) on the rights of persons with intellectual disabilities and effective communication techniques are not available in any of the five countries. However, a training event reflecting on the rights of persons with intellectual disabilities and effective communication techniques was *offered* for judges and other court staff in 2008 in **Hungary**.

No information is available regarding any proposed elements of compulsory training on the rights of persons with intellectual disabilities and effective communication techniques for officials in the justice system in any of the project countries.

*Lack of compulsory or even non-compulsory training offered for officials in the justice system (lawyers, judges, clerks, notaries, etc.) on the rights of persons with intellectual disabilities, including effective communication techniques, means that the judiciary is not trained about their obligation to respect the rights of persons with intellectual disabilities. This training gap may mean that:*

- *persons with intellectual disabilities do not enjoy legal capacity on an equal basis with others;*
- *enjoyment of legal capacity by persons with intellectual disabilities is not ensured in the field of access to justice;*
- *persons with intellectual disabilities are not provided with access to support in the exercise of legal capacity in the area of access to justice;*
- *procedural and age-appropriate accommodations are not ensured for persons with intellectual disabilities;*
- *reasonable accommodations are not ensured for persons with intellectual disabilities in the field of access to justice;*
- *persons with intellectual disabilities are not enabled to take part in proceedings as direct and indirect participants;*
- *persons with intellectual disabilities are not provided with access to information and communication.*



## 5. Conclusions

The report highlights the interrelated nature of guardianship law and policy, and access to justice for adults with intellectual disability. The five jurisdictions under consideration vary as to the specific nature of their guardianship systems, and in the available mechanisms for achieving access to justice.

Overall, the findings of the report highlight major gaps in providing for equal access to justice for people with intellectual disabilities. However, these findings should not come as a surprise. The United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) has so far provided compliance reviews (or ‘Concluding Observations’) to over a dozen States Parties to the CRPD. The CRPD Committee has repeatedly directed governments to review guardianship and to take actions to replace guardianship laws with supported decision-making.<sup>264</sup> As noted in the Introductory Chapter, the first General Comment directs that guardianship laws inherently restrict the legal capacity of persons with disability on an unequal basis with others. This report has provided specific examples of how this violation takes place at the domestic level in the jurisdictions considered. These findings must be contextualized by the well-documented fact that no jurisdiction in the world can be seen to fully comply with Article 12 of the CRPD.

In achieving the transition from substituted to supported decision-making regimes, it is clear that governments are uncertain as to how they can fully realise the ‘paradigm shift’ of Article 12, including with regard to Article 13 of the CRPD. Even governments who are more advanced in this respect, such as Ireland and Hungary, have remained cautious in developing alternatives that would fully replace substituted decision-making. Hence, abandoning the functional assessment of mental capacity as a cornerstone of laws relating to persons with intellectual disability remains an ongoing challenge. This is not to say that momentum for change is lacking, nor that it cannot be steered by advocates seeking to bring about change. Each jurisdiction under consideration can point to changes in law and practice over the past ten years that have improved the rights of adults with intellectual disabilities in accessing justice and in exercising their legal capacity on an equal basis with others.

A number of specific laws and practices in different countries highlight the immediate steps that governments can take to signal this shift. For example, there appears to be momentum in most jurisdictions to prioritise the will and preference of the relevant person with intellectual disability. This includes ensuring such persons can meet with judges and other court officials during court proceedings. Hence, the jurisdictions under consideration in this report can generally be seen to be taking a progressive or ‘gradualist’ approach to realising the rights set out in Article 12 and 13.<sup>265</sup>

In contrast, however, the CRPD Committee directs that the ‘right to equality before the law has a long history of recognition as a civil and political right.’<sup>266</sup> This is significant because under

<sup>264</sup> CRPD Committee, ‘Concluding Observations’,

[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5) last accessed 23 June 2014

<sup>265</sup> A possible exception to this is Ireland, where the *Assisted Decision-Making (Capacity) Bill 2013* can be seen to constitute one of the most strident attempts to remove substituted decision-making in favour of prioritizing the will and preference of the person and providing support to exercise legal capacity.

<sup>266</sup> United Nations Committee on the Rights of Persons with Disabilities, ‘Draft General comment on Article 12 of the Convention – Equal Recognition before the Law,’ above n 1





international human rights law civil and political rights are subject to immediate realisation (and not ‘progressive’ or ‘gradualist’ approaches). The CRPD Committee directs States Parties to *‘take steps to immediately realize the rights within Article 12, including the right to support for the exercise of legal capacity.’*<sup>267</sup> Hence, there remains a considerable ‘implementation gap’ noted at the beginning of this report.

To address this gap, the report makes a number of recommendations which are summarised below.

1. That governments consider implementing ongoing mechanisms to replace the framework of guardianship, mental capacity assessments and ‘best interests’ decision-making with a supported decision-making regime. This could include:
  - a. undertaking law reform to replace assessments of mental capacity with the provision of supports to exercise legal capacity;
  - b. prioritising the will and preference of the relevant person with intellectual disability rather than a ‘best interests’ model;
  - c. developing supported decision-making in policy and practice by drawing on the emerging range of good practices being promoted internationally;
  - d. making clear information and resources available to support people to challenge guardianship orders and arrange alternative supports that do not restrict legal capacity.
2. That governments consider implementing ongoing mechanisms to promote access to justice for people with intellectual disabilities. This could include:
  - a. auditing specific barriers in access to justice, for example, the lack of reasonable accommodations regarding speech and language for people with intellectual disabilities in legal proceedings;
  - b. collecting data on the types of support that people with disabilities are requesting or availing of in legal proceedings;
  - c. ensuring that legal proceedings – from courtrooms to administrative tribunals and reporting mechanisms – are accessible to people with disabilities in general;
  - d. reforming laws so that denial of reasonable accommodation is deemed by law to be an act of disability-based discrimination.

It is possible to view the implementation gap in law and policy from a broad perspective; for example, by considering how law and policy based on the guardianship, mental capacity and ‘best interests’ framework is being maintained (rather than a supported decision-making regime as required under the CRPD). It is also possible to view this gap at the micro-level, with consideration of specific barriers in access to justice; for example, the lack of reasonable accommodations regarding speech and language for people with intellectual disabilities in legal proceedings, such as through the use of speech therapists and other such intermediaries specialising in interpretive support. In the

<sup>267</sup> Ibid (emphasis added)



specific area of guardianship, there was a surprising lack of data on cases which could facilitate a shift from substituted decision-making systems to ‘supported decision-making regimes’. For example, researchers do not know how many cases were initiated to challenge the appointment of guardians or how many cases were successful or unsuccessful in challenging the guardianship order and applying for restoration of legal capacity. This observation is supported by a 2010 European Commission report which stated, ‘there is not much quantitative Europe-wide information about rights such as equal recognition before the law (Article 12) and access to justice (Article 13), but there are clear indications that this is a key problem area.’<sup>268</sup> As noted in the Executive Summary, it would be an effective initial step to build a proper statistic report at the national and European level of current guardianship practices.

Finally, it is important to reiterate that the role of guardians, curators, and tutors are often considered as supportive, empowering and enabling towards adults with intellectual disabilities. This raises questions about whether the trend to move away from guardianship systems can retain some existing forms of support from those systems in ways that enhance the rights of adults with intellectual disabilities. The paradoxical role of guardianship amid this transitional period continues to challenge people with disabilities and their supporters, including advocates, policymakers, researchers, and others wishing to promote and uphold the rights of people with intellectual disability.

<sup>268</sup> European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. Brussels, 15.11.2010. COM(2010) 636 final. SEC(2010) {SEC(2010) 1323} {SEC(2010) 1324}. Para 3.1.2.2



## Annex I: Annotated Bibliography

This annotated bibliography lists materials that address the rights to legal capacity and access to justice of persons with intellectual disabilities. They are compiled from the five countries and also from the European level. This list is comprised of both *academic literature* including legal texts, books, academic journals, judgments of national courts; as well as *grey literature* including civil society documents, government documents and other relevant sources.

Country	Source	Description
Bulgaria	<i>Act on Individuals and Family</i> (Закон за лицата и семейството). Available in Bulgarian at: <a href="http://lex.bg/bg/laws/ldoc/2121624577">http://lex.bg/bg/laws/ldoc/2121624577</a>	The law provides for the equalisation of the legal status of persons with intellectual and psychosocial problems who are unable to take care of their own affairs due to their disability to the minors and adolescents.
	<i>Family Code</i> (Семеен кодекс). Available in Bulgarian at: <a href="http://www.lex.bg/bg/laws/ldoc/2135637484">http://www.lex.bg/bg/laws/ldoc/2135637484</a>	The Code provides the material law for guardianship, the scope, the persons who can be placed under guardianship, the functions of the guardianship authorities.
	<i>Civil Procedure Code</i> (Граждански процесуален кодекс) Available in Bulgarian at: <a href="http://lex.bg/laws/ldoc/2135558368">http://lex.bg/laws/ldoc/2135558368</a>	The Code provides for the procedure under which the people with intellectual disabilities are to be placed under guardianship or their guardianship would be lifted.
	Bulgarian Helsinki Committee & Bulgarian Institute for Personal Relations: <i>Needs Assessment of the Structures Involved in the Process of Deinstitutionalisation of the Care of Persons with Severe Mental Diseases and Mental Disabilities</i> , Monitoring report, August 2008 - August 2009, Sofia. Available in Bulgarian.	The report summarizes the outcomes of a fieldwork research (service users and service providers were interviewed and documents were reviewed by researchers) of several regions (institutions and services) and the developments of community-based services in them as well as how guardianship is developed for both people with intellectual disabilities and mental health problems so that deinstitutionalisation is made possible.
	MBMD Agency: <i>Assessment of the Mental Health Care System Functioning on the Territory of Sofia Municipality</i> , sociological research of the MBMD agency, June-August	This sociological research is based on questionnaires filled by people with 'mental problems' or their relatives and the focus was on the opinions of



	2009, p.20-21. Available in Bulgarian	people with mental problems in terms of their access to services – social and medical.
	Ministry of Justice working group on the implementation of Article 12 of CPRD in the national legislation: <i>Concept paper for amendments in the national legislation in order to comply with the standards of art.12 of the CRPD</i> adopted by Council of Ministers on 14 November 2012. Available in Bulgarian at: <a href="http://www.strategy.bg/Publications/View.aspx?lang=bg-BG&amp;Id=138">http://www.strategy.bg/Publications/View.aspx?lang=bg-BG&amp;Id=138</a>	The Concept paper focuses on how the guardianship system in Bulgaria should be changed to supported decision-making system. It explains why this is needed and why the current system of plenary and partial guardianship is not acceptable. It also explains what kind of people with what kind of needs need to use supported decision systems and who should be in charge to ensure such systems and what kind of legislative amendments are needed for this.
	Bulgarian Centre for Non-Profit Law: <i>Ensuring opportunities and environment in which people with intellectual disabilities and psycho-social problems exercise their rights</i> (Осигуряване на възможности и среда, в която хората с интелектуални затруднения и психично-здравни проблеми упражняват правата си) – report on the guidelines for change of policies, 2014. Available in Bulgarian at: <a href="http://equalrights.bcnl.org/uploadfiles/documents/izsledvaniq/guidelines_policy_research_summary_content.pdf">http://equalrights.bcnl.org/uploadfiles/documents/izsledvaniq/guidelines_policy_research_summary_content.pdf</a>	The report analyses the gaps in Bulgarian legislation and practice which hinder the introduction of supported decision making in the spheres of access to services and social services, employment, healthcare, housing, access to legal aid, management of property and financial issues, personal and family relationships. It also points out how the policies and legislation should be amended to comply with the UNCRPD.
	De Passarel Foundation & Bulgarian Centre for Non-Profit Law: <i>Research about the effect and the economic profit of the supported decision making</i> , 2014. Available in Bulgarian at: <a href="http://www.equalrights.bcnl.org/uploadfiles/documents/izsledvaniq/cost_effectiveness_resume_final.pdf">http://www.equalrights.bcnl.org/uploadfiles/documents/izsledvaniq/cost_effectiveness_resume_final.pdf</a>	At first an assessment of the quality of life and an assessment of the level of dependency and personal perspective were carried out for each of the participants. Six months later after supported decision making was applied assessments were done again. For quality of life assessment a scale was used with three factors (independence, social inclusion and welfare) in eight spheres of life (personal development, self-identification, interpersonal relationships, social inclusion, rights, emotional



		condition, physical condition, material condition). In all participants' cases the quality of life was improved with 10 % within six months. The research estimates that the non-material profits of supported decision making are visible. In terms of material profits, proper supported decision-making system is assumed to increase not only the income of people with disabilities but the savings of the state budget as well.
	Constitutional Court: Decision 12/17.07.2014 issued by Constitutional Court in the case 10/2014. The decision is available in Bulgarian at: <a href="http://constcourt.bg/acts">http://constcourt.bg/acts</a> .	The decision highlights that "the lack of detailed legislative regulation of the legal regime concerning incapacitated adults leads not only to the limitation of those rights, the exercise of which carries a risk to the interests of incapacitated, third parties or the society, but also limits the exercising of unreasonably wide range of rights, including the constitutional ones. (...) The current legislative framework does not take into account the requirements of the CRPD – the restrictions of the rights of such persons to be proportionate to their condition, to apply for the shortest possible term and to be subject to regular review by an independent body."
	Sofia Regional Court: Sofia Regional Court Decision, dated 18.02.2013 in civil case 4667/2012.	In this case the plenary guardianship of a person with intellectual disability was lifted but he was placed under partial guardianship. The case was initiated by the guardian who requested restoration of legal capacity or alternatively – change of the scope of guardianship from plenary to partial. The complaint was filed by the person under guardianship who participated in the proceedings by a special



		representative appointed by the court. The person concerned and a therapist who knows the person well were heard by the court.
	Vidin Regional Court: Case No. 178/2014 z. Pending.	This complaint concerns a woman with intellectual disability under guardianship who filed a complaint asking for restoration of her legal capacity. The complaint was signed by her guardian. The case was initiated with the argument that the woman receives sufficient assistance in the community which supports and compensates her disability and she is in a condition to make independent decisions.
Finland	<i>Act on Continuing Powers of Attorney</i> (648/2007)	Relevant legislation.
	<i>Act on Organization of Guardianship Services</i> (575/2008)	Relevant legislation.
	<i>Administrative Procedure Act</i> (434/2003)	Relevant legislation.
	<i>Administrative Judicial Procedure Act</i> (586/1996)	Relevant legislation.
	<i>Code of Judicial Procedure</i> (4/1734)	Relevant legislation.
	<i>Guardianship Services Act</i> (442/1999) (Laki holhoustoimesta.) An unofficial English translation is available at: <a href="http://www.finlex.fi/fi/laki/kaannokset/1999/en19990442.pdf">http://www.finlex.fi/fi/laki/kaannokset/1999/en19990442.pdf</a>	Relevant legislation.
	Kangas Urpo: <i>Uskottu mies holhousoikeuden järjestelmässä</i> , Vantaa 1987	Uskottu mies holhousoikeuden järjestelmässä, Vantaa 1987. ("Trustee in the system of the Guardianship Services Act", not official translation)
	Kuuliala, Matti: <i>Edunvalvontaan esitetyn kuuleminen alioikeudessa</i> , Helsinki 2012	("Hearing of an alleged incapacitated person in the district court", not official translation). This study is the first doctoral dissertation concerning guardianship in Finland. The subject of the study was hearing of alleged incapacitated adult person in a district court. Study focused on cases in which the petitioner is a guardianship authority



		because it is rare that other parties file a petition in these matters. The aims of the study were how the hearing of an alleged incapacitated person in a district court should be conducted, how hearings take place in district courts in practice and analyze the tension between the procedural nature of guardianship matters and the principle of hearing.
	Ministry of Justice: <i>Arviomuistio viittomakielilain tarpeesta</i> 30.1.2013. Osoitteessa: <a href="http://oikeusministerio.fi/material/attachments/om/valmisteilla/lakihankkeet/kiellisetjaku/lttuurisetoikeudet/6Kbdkw4qN/Arviomuistio_vittomakielilaki[1].pdf">http://oikeusministerio.fi/material/attachments/om/valmisteilla/lakihankkeet/kiellisetjaku/lttuurisetoikeudet/6Kbdkw4qN/Arviomuistio_vittomakielilaki[1].pdf</a>	Language Act (6.6.2003/423) concerns only using of Finnish or Swedish in authorities and in courts. Sámi Language Act (15.12.2003/1086) concerns using Sámi in the same contexts. There has not been an act for other languages like sign language but Ministry of Justice has evaluated the need for this kind of act for sign language in Finland. Ministry of Justice came into conclusion that this is needed but it should be implemented as a general act concerning the right to use sign language.
	Saarenpää, Ahti: <i>Holhouksesta edunvalvontaa, Pohjois-Suomen tuomarikoulun julkaisuja</i> 1-2/2000, p. 141-196.	Holhouksesta edunvalvontaa, Pohjois-Suomen tuomarikoulun julkaisuja 1-2/2000, p. 141-196 "From the trustee to legal guardianship, Northern Finland Judge School publications, <i>not official translation</i> ). Aspects of starting the legal guardianship accordance with the Guardianship Services Act.
	Tornberg, Johanna: <i>Legal Quality in Finnish Guardianship Services</i> . In Sweighofer, Erich – Gaster, Jens – Farrand, Benjamin (ed.): KnowRight 2010: Knowledge Rights – Legal, Societal and Related Technological Aspects. Conference Proceedings May 5-6, 2010, University of Vienna, Austria. Österreichische Computer Gesellschaft 2010. p. 151-161	
	Tornberg, Johanna: <i>Edunvalvonta</i> ,	This study is the second doctoral





	<i>itseääräämisoikeus ja oikeudellinen laatu</i> , Rovaniemi 2012 "Guardianship services, self-determination and legal quality."	dissertation concerning guardianship in Finland. It examined procedural legislation, material legislation and legislation concerning information and information processing as a whole in the area of guardianship, especially in local register offices. Two areas in particular were chosen for analysis: One was where a person files a petition on his or her own initiative requesting appointment of a guardian, the other was where donee applies to a registry office to confirm a continuing powers of attorney. Both procedures were examined as information processes: starting from the first contact with the guardianship authority and ending when the information related to the case is expunged from the authority's archives and registers.
	Välimäki, Pertti: <i>Edunvalvontaoikeus</i> , 2013. ("Legal Guardianship", not official translation)	This book contains basic information about guardianship.
	Supreme Court: Case No. KKO:2005:46	In the KKO:2005:46 District Court had dismissed without considering merits A's application on dismissing A's guardian because the request was not specific enough. By A's statement and medical certificate it was obvious that A wasn't due his medical condition able to handle the matter by himself. On this basis Supreme Court's ruling was that District Court should have appointed a counsel or guardian for trial for A before continuing the processing of the matter.
	Supreme Court: Case No. KKO:2009:7	This case concerns a senior citizen. It had been proved that A was not anymore able to take care of her financial affairs by herself because of her diminished health. She was opposed to appointing a guardian



		for her because her affairs were taken care of by his son and the bank. Supreme Court decided not to appoint a guardian in this case because of this. A's affairs were already taken care of and even though A had diminished health, it was not enough a reason to appoint a guardian.
	Supreme Court: Case No. KKO:2009:68	In the case of KKO:2009:68 the Supreme Court decided that when A had given a consent to local register office to apply a guardian for A from District Court, District Court did not have to reserve an opportunity to be heard to A. This ruling was raised strong criticism because it violated Guardianship Services Act's Section 73 so clearly. Even though local register office hears the person before making the application to the District Court, this does not mean that court does not have an obligation to hear that person anymore. Hearing in court has a different meaning. If the person concerned opposes appointment of a guardian to him/her, court has to justify in its decision why guardian has been appointed despite of the resistance if the guardian is appointed
	Supreme Court: Case No. KKO:2011:67	In the case KKO:2011:67 injured party B had received a brain injury in a traffic accident. There had been no guardian appointed to him to pre-trial investigation. The question was did the B's father have the right to ask on behalf of his son the prosecutor to bring charges for negligent bodily injury (Criminal Code of Finland Chapter 21 Section 10). According to Criminal Code of Finland Chapter 21 Section 16



		subsection 2 the public prosecutor may bring charges for the negligent bodily injury only if the injured party reports the offence for the bringing of charges. Finnish Supreme Court stated that B was unable to take of his affairs in this matter because of his injuries. B's father's actions were necessary in this situation. Because B's father had asked on behalf of his son the prosecutor to bring charges in pre-trial investigation the right to bring charges was not become time-barred.
	Supreme Court: Case No. <i>KKO:2012:109</i>	In Supreme Court's decision <i>KKO:2012:109</i> Supreme Court Stated that A would have needed a counsel or guardian for trial in view of the legal safeguards. She had atypical autism, moderate intellectual disability and conduct disorder which required treatment. Her literacy was good but she had difficulties in reading comprehension. Her speaking was clear but she had difficulties in listening comprehension. Because of this the suitable way to hear A would have been an oral hearing in court. A counsel or guardian for trial would have been able to support A in this.
	Parliamentary Ombudsman: File No. <i>EOA 3637/4/09</i>	Parliamentary Ombudsman has pointed out that hearing the person concerned should be the first and most important way of investigating the person's situation especially when local register office has powers to appoint the guardian.
France	<i>Civil Code</i> (Code Civil). Available at: <a href="http://www.legifrance.gouv.fr/affichCode.do?cidTexte=LEGITEXT000006070721">http://www.legifrance.gouv.fr/affichCode.do?cidTexte=LEGITEXT000006070721</a>	Act n° 2007-308 of 5th March 2007 brought many legal capacity related changes to civil law
	<i>Circular of implementation (JUSC0901677C)</i> <a href="http://www.textes.justice.gouv.fr/art_pix/boj_20090001_0000_0036.pdf">http://www.textes.justice.gouv.fr/art_pix/boj_20090001_0000_0036.pdf</a>	Relevant legislation.



	Report from IGAS (General Inspection of social affairs), Isabelle Rougier et Cécile Waquet, July 2014, "Financing the legal guardianship system" <a href="http://www.igas.gouv.fr/IMG/pdf/Rapport_2014-071R_DEF.pdf">http://www.igas.gouv.fr/IMG/pdf/Rapport_2014-071R_DEF.pdf</a>	This report is a very complete description of the current estate of legal guardianship (and not only on financial issues) and mentioned many times by professionals. It shows which changes have occurred after the law of 2007 and how difficult it is to implement the law with the lack of means.
	Decree n° 2009-1628 <a href="http://legifrance.gouv.fr/affichTexte.do;jsessionid=01380B84551D3C853E2D7D48935D4C3B.tpdjo05v_1?cidTexte=JORFTEXT000021527461&amp;dateTexte=20140620">http://legifrance.gouv.fr/affichTexte.do;jsessionid=01380B84551D3C853E2D7D48935D4C3B.tpdjo05v_1?cidTexte=JORFTEXT000021527461&amp;dateTexte=20140620</a>	This decree concerns implementation of changes regarding 'appeal.'
	Decree n° 2007-1702 <a href="http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000017572441&amp;fastPos=1&amp;fastReqId=1306959493&amp;categorieLien=cid&amp;oldAction=rechTexte">http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000017572441&amp;fastPos=1&amp;fastReqId=1306959493&amp;categorieLien=cid&amp;oldAction=rechTexte</a>	This decree concerns implementation of 'mandate for future protection.'
	Decree n° 2008 1276 <a href="http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000019876237&amp;fastPos=1&amp;fastReqId=203281947&amp;categorieLien=cid&amp;oldAction=rechTexte">http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000019876237&amp;fastPos=1&amp;fastReqId=203281947&amp;categorieLien=cid&amp;oldAction=rechTexte</a>	This decree concerns implementation of changes regarding curatorship and tutorship and social care.
	Decree n° 2008 1484 <a href="http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000020017088&amp;fastPos=1&amp;fastReqId=1106668480&amp;categorieLien=cid&amp;oldAction=rechTexte">http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000020017088&amp;fastPos=1&amp;fastReqId=1106668480&amp;categorieLien=cid&amp;oldAction=rechTexte</a>	This decree concerns implementation of changes regarding property rights.
	Decree n° 2008 1485 <a href="http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000020017181&amp;fastPos=1&amp;fastReqId=484145598&amp;categorieLien=cid&amp;oldAction=rechTexte">http://legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000020017181&amp;fastPos=1&amp;fastReqId=484145598&amp;categorieLien=cid&amp;oldAction=rechTexte</a>	This decree concerns implementation of changes regarding medical certificates.
	Court of Auditors (Cour des Comptes): <i>Report to the Senat Finance committee.</i> (Communication à la commission des finances du Sénat. La réforme de la protection juridique des majeurs), November 2011. Available in French at : <a href="http://www.senat.fr/rap/r11-315/r11-315-annexe.pdf">http://www.senat.fr/rap/r11-315/r11-315-annexe.pdf</a>	This report addresses the costs of the 2007 reform and explains the first difficulties to implement it.
	MM. Éric BOCQUET et Edmond HERVÉ (Sénat):	



	<p><i>Information report n 315 in the name of Finance Committee about investigation of Court of Auditors on Law 2007-308 of 5th March 2007.</i> (Rapport d'information n315 au nom de la commission des finances sur l'enquête de la Cour des comptes relative à l'évaluation de la loi n 2007-308 du 5 mars 2007 portant réforme de la protection juridique des majeurs), Available in French at: <a href="http://www.senat.fr/rap/r11-315/r11-3151.pdf">http://www.senat.fr/rap/r11-315/r11-3151.pdf</a></p>	
	<p>Brigitte Munoz Perez and Caroline Moreau (Ministry of Justice, Direction of Civil Law, Office of civil justice control): <i>2 years of implementation of the Law of 5th March 2007.</i> (Deux ans d'application de la Loi du 5 mars 2007 portant réforme de la protection juridique des majeurs devant les juges des tutelles 2009-2010)</p>	
	<p>BOUTARIC Rose (Report of the Economical and Social Council to prepare the law): <i>Reforming guardianship</i> (Réformer les tutelles), octobre 2006. Available in French at: <a href="http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/064000740/0000.pdf">http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/064000740/0000.pdf</a></p>	<p>This report addresses why the previous act of 1968 doesn't work anymore and why and how to reform guardianship in France.</p>
	<p><i>National Parliament Report</i>, January 2007 : <a href="http://www.assemblee-nationale.fr/12/rapports/r3557.asp#P1545_97358">http://www.assemblee-nationale.fr/12/rapports/r3557.asp#P1545_97358</a></p>	<p>This report is the genesis of the 2007 Act.</p>
	<p>CNAPE, la FNAT, l'UNAF et l'Unapei: <i>White Paper on legal protection</i> (Livre blanc sur la protection juridique des majeurs). <a href="http://www.unapei.org/IMG/pdf/LivreBlancProJuri.pdf">http://www.unapei.org/IMG/pdf/LivreBlancProJuri.pdf</a></p>	<p>Associations of parents of persons with intellectual disabilities, federation of legal guardians and other institutions offer an analysis of the 2007 Act. The white paper focuses on the need to strengthen the judicial system by employing more judges. There is a need to train judges, medical professionals, clerk of courts and all the persons who play a role in the decision-making process on disability. There is also a need to elaborate common tools such as evaluation scales to give to</p>



		the judges and the medical professionals the possibility to apply the law and its principles of necessity, subsidiarity and proportionality. The main issue for Persons with intellectual disabilities is communication in order to have full access to justice.
	Agence nationale de l'évaluation et de la qualité des établissements et services sociaux et médico-sociaux (National Agency for Evaluation and Quality of Establishments and Service Providers): <i>Participation des personnes protégées dans la mise en œuvre des mesures de protection. Recommandations de bonnes pratiques professionnelles</i> . (Recommendation on good practices: participation of protected people in guardianship measures), 2012. Available in French at: <a href="http://www.anesm.sante.gouv.fr/IMG/pdf/Anesm_09_protection-juridique_CS4_web.pdf">http://www.anesm.sante.gouv.fr/IMG/pdf/Anesm_09_protection-juridique_CS4_web.pdf</a>	This is a document aiming to help legal guardians to use supported decision-making with people with Intellectual disabilities.
	Benoît Heyrault & Pierre Vidal Naquet: <i>Consentir sous tutelle. La place du consentement chez les majeurs places sous mesure de protection</i> . (Agreement under guardianship. Place of the consent for adults under protection). In Tracés n 378. Available in French at: <a href="http://traces.revues.org/378">http://traces.revues.org/378</a>	This is an analysis of the concept of will and consent in the framework of guardianship by the most renowned sociologist.
	Martine Dutoit: <i>Réflexions sur la mise en œuvre de la Loi du 5 mars 2007 portant réforme de la protection juridique de majeurs</i> (Reflection on the implementation of the Act of 5 March 2007 reforming the legal protection of adults). <a href="http://advocacy.fr/upload/Reflexions_sur_la_mise_en_uvre_de_la_loi.pdf">http://advocacy.fr/upload/Reflexions_sur_la_mise_en_uvre_de_la_loi.pdf</a>	This article proposes a reflection on the implementation of the Law of March 5th, 2007 reforming the legal protection of adults from an action of support for the access to the rights and resort regularly seized with problem met within the framework of the execution of these protective measures or wishing their levying. It is a question of reporting from the point of view of the users of the mental health addressing or participating in the action of the association Advocacy. Also the opportunity to present the propositions made on the occasion



		of the ratification by France the Convention on the rights of persons with disabilities, still little known, while concerning the measures of accompaniment in the decision-making which modify the approach and in the end the practices of protection of the persons in situation of 'vulnerability' so that the persons, about is the manners with which they are 'labelled', can be recognized as persons at first and full members of society.
	Projet de Loi: <i>Modernisation et simplification du droit et des procédures</i> (Bill on Simplifying the laws and procedures). Available in French at: <a href="http://www.assemblee-nationale.fr/14/dossiers/simplification_droit_justice_affaires_interieures.asp">http://www.assemblee-nationale.fr/14/dossiers/simplification_droit_justice_affaires_interieures.asp</a>	One of the aspects of this new law is that in certain situations (e.g. regarding persons with profound intellectual disabilities) the mandatory review of curatorship and tutorship may be extended to even 30 years.
Hungary	Act V of 2013 on the Civil Code. Available in Hungarian at: <a href="http://www.complex.hu/kzldat/t1300005.htm/t1300005_0.htm">http://www.complex.hu/kzldat/t1300005.htm/t1300005_0.htm</a>	Relevant legislation.
	Act CLV of 2013 on Supported decision-making	Relevant legislation.
	Act III of 1952 on the Code of Civil Procedure	Relevant legislation.
	Government Decree 149/1997 (IX. 10.) on guardianship authorities, child protection and guardianship proceeding.	Relevant legislation.
	Guide for the Rules of Procedure to be followed by guardianship authorities regarding supported decision-making, Summarized Rules of Procedure for guardianship authorities. (Without author, editor, date etc) Available in Hungarian at <a href="http://www.macsgyoe.hu/downloads/szakmai_anyagok/tdeljarasrend.pdf">http://www.macsgyoe.hu/downloads/szakmai_anyagok/tdeljarasrend.pdf</a>	
	Lovász László and Sziklai István (eds.): <i>The current status of the system assisting and regulating persons with disabilities in Europe and Hungary and the recommendations formulated in this respect by national interest groups</i> . Budapest, EPP Group, 2014. Available in Hungarian at:	Some of the chapters of the publication were prepared by the representatives of the organisations of the national interest groups of representing the interests of people with disabilities, including the Hungarian Autistic Society (AOSZ),





	<a href="http://issuu.com/carpinelli/docs/rendszerhelyzet_fogy_ep?e=0/8032333">http://issuu.com/carpinelli/docs/rendszerhelyzet_fogy_ep?e=0/8032333</a>	the Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ), the National Federation of Physically Disabled Persons' Associations (MEOSZ), the Hungarian Federation of the Blind and Partially Sighted (MVGYOSZ), the Hungarian Association of the Deaf and Hard of Hearing (SINOSZ) and the National Deafblind Association (SVOE).
	Hand in Hand Foundation: <i>Esetjogi Tanulmányfüzet</i> (Booklet of Case Law Studies), 2009. Available in Hungarian at: <a href="http://www.kezenfogva.hu/nehagydmagad/fil-es/nehagydmagad2_2v.pdf">http://www.kezenfogva.hu/nehagydmagad/fil-es/nehagydmagad2_2v.pdf</a>	
	Fülöpné Mezei Anikó, Kovács Ibolya: <i>Fogyatékos személyek jogai és jogsérelmei</i> (Right and infringement of rights of persons with disabilities). Betegjogi, Ellátottjogi és Gyermekjogi Közalapítvány, Budapest 2009. Available in Hungarian at: <a href="http://tamogatoweb.hu/index.php/e-konyvtar/74-szakmai-anyagok/268-fogyatekos-szemelyek-jogai-es-jogserelmei">http://tamogatoweb.hu/index.php/e-konyvtar/74-szakmai-anyagok/268-fogyatekos-szemelyek-jogai-es-jogserelmei</a>	
	National Centre for Patients' Rights and Documentation (OBDK): <i>Annual Report, 2013</i> . Available in Hungarian at: <a href="http://www.obdk.hu/UserFiles/obdkbeszamolo2013.pdf">http://www.obdk.hu/UserFiles/obdkbeszamolo2013.pdf</a>	
	Commissioner for Fundamental Rights: <i>Report in case No. AJB-1199/2013</i> (Related cases: AJB-1197/2013; AJB-1198/2013.; AJB-1200/2013.; AJB-1201/2013; AJB-1202/2013). 2013. 48-49. Available in Hungarian at <a href="http://www.ajbh.hu/documents/10180/111959/201301199.doc">www.ajbh.hu/documents/10180/111959/201301199.doc</a>	The Commissioner for Fundamental Rights launched a project in 2013 under the title "Kommunikációval az egyenlő méltóságért – Befogadó beszéd kontra gyűlöletbeszéd" [Communication as a means to achieve equal dignity – Inclusive speech versus speech of hatred] and conducted several thematic examinations as part of this project. The Commissioner highlighted that a real change of attitude must take place among the judicial and law enforcement bodies alike. Such changes in attitudes may be realized



		by means of education, training and further training in all forms and on all levels from early childhood to the training of the members of the judicial and law enforcement bodies.
	Mental Disability Advocacy Centre (MDAC) – <i>a study prepared by Benkó Boglárka, Fiala János and Gombos Gábor on the rights of persons living with psycho-social disabilities in the light of the “UN Convention on the Rights of Persons with Disabilities”.</i>	
	<i>Rights of persons with disabilities or disability rights? – Parallel report of the Hungarian civil caucus on the UN Convention, 2010.</i>	
	Mental Disability Advocacy Center and the Hungarian Civil Liberties Union (TASZ): <i>Written submission on the Follow-up to the Concluding Observations on Hungary CRPD/C/HUN/CO/1 to the Committee on the Rights of Persons with Disabilities, Tenth Session 2-13 September 2013.</i> Available at: <a href="http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/HUN/INT_CRPD_NGS_HUN_16889_E.doc">http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/HUN/INT_CRPD_NGS_HUN_16889_E.doc</a>	
	Hungarian Disability Caucus: <i>Hungary – List of issues submissions. 7th session of the UN Committee on the Rights of Persons with Disabilities.</i> April 2012. Available at: <a href="http://www2.ohchr.org/SPdocs/CRPD/7thsession/HungarianDisabilityCaucus.doc">http://www2.ohchr.org/SPdocs/CRPD/7thsession/HungarianDisabilityCaucus.doc</a>	
	Mental Disability Advocacy Center: <i>Guardianship and Human Rights in Hungary. Analysis of Law, Policy and Practice 2007.</i> Available at: <a href="http://mdac.info/sites/mdac.info/files/English_Guardianship_and_Human_Rights_in_Hungary.pdf">http://mdac.info/sites/mdac.info/files/English_Guardianship_and_Human_Rights_in_Hungary.pdf</a>	
	Mental Disability Advocacy Center and the Hungarian Civil Liberties Union (TASZ): <i>Written submission on the Follow-up to the Concluding Observations on Hungary CRPD/C/HUN/CO/1 to the Committee on the Rights of Persons with Disabilities, Tenth Session 2-13 September 2013.</i>	



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	Equal Treatment Authority – <i>legal cases</i> . Available in Hungarian at: <a href="http://www.egyenlobanasmod.hu/jogesetek/jogesetek">http://www.egyenlobanasmod.hu/jogesetek/jogesetek</a>	
Ireland	<i>Lunacy Regulation (Ireland) Act 1871</i> . Available at <a href="http://www.irishstatutebook.ie/1871/en/act/pub/0022/print.html">http://www.irishstatutebook.ie/1871/en/act/pub/0022/print.html</a>	Relevant existing law which currently mandates the ward of court system.
	<i>Scheme of Mental Capacity Bill 2008</i> . Available at: <a href="http://www.inis.gov.ie/en/JELR/Pages/Scheme_of_Mental_Capacity_Bill_2008">http://www.inis.gov.ie/en/JELR/Pages/Scheme_of_Mental_Capacity_Bill_2008</a>	The Scheme proposed a functional assessment of capacity, and specified that this process would take place in the ordinary court system. The Scheme of the Mental Capacity Bill provided for an assessment of mental capacity which would lead to a removal or restriction of the individual's legal capacity.
	<i>Assisted Decision-Making (Capacity) Bill 2013</i> . Available at <a href="http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf">http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf</a>	Proposed Bill to harmonise Irish law with the CRPD.
	Anne-Marie O'Neill: <i>Wards of Court in Ireland</i> . Dublin, First Law, 2004	It sets out and critiques the wardship procedure and specifically focuses on admission to wardship, how wardship can be revoked and the role of guardians
	Anne-Marie O'Neill: <i>Irish Mental Health Law</i> . Dublin, First Law, 2005	It contains analysis of legal capacity in private law, in the context of personal and family relationships and under public law.
	Whelan: <i>Mental Health Law And Practice - Civil And Criminal Aspects</i> . Dublin, Thomson Reuters (Professional) Ireland Ltd., 2009	Chapter 13 of Whelan's text examines the wards of court system, issues of capacity and proposals for reform of the current system.
	Supreme Court: <i>Eastern Health Board v. M.K [1999] 2 I.R. 99</i>	The Supreme Court underlines in its decision that "wardship proceedings must be fair and in accordance with constitutional justice. The constitutional rights of all parties ..., must be protected. Where rights are in conflict they must be balanced appropriately. Due process must be observed by the court while



		exercising this unique jurisdiction. Consequently, if a legal right or a constitutional right is to be limited or taken away by a court this must be done with fair procedures. Fundamental principles ... apply. There must be fair procedures.” (at 111.)
	Anne-Marie O’Neill: <i>Wardship in Ireland</i> (2005) 2 Irish Journal of Family Law, 2-8	O’Neill’s article provides a comprehensive overview of the current system of substitute decision-making in Ireland.
	Suzanne Doyle and Eilionóir Flynn: <i>Ireland’s ratification of the UN convention on the rights of persons with disabilities: challenges and opportunities</i> (2013) 41(3) British Journal of Learning Disabilities, p. 171–180	Doyle and Flynn provide both an analysis of the current wardship system in light of Article 12 of the CRPD as well as the efforts of civil society in advance of the publication of the 2013 Bill. It concludes with setting out and commenting on government statements on the content of the forthcoming published legislation and makes tentative remarks based on this. This article provides an up to date assessment of the implications of Article 12 for Ireland and the barriers to accessing justice which persons with intellectual disabilities are faced in the current system.
	Centre for Disability Law and Policy at NUIG, Amnesty International, and others: <i>Essential Principles: Irish Legal Capacity Law</i> . 2012. Available at <a href="http://www.amnesty.ie/sites/default/files/report/2012/04/PRINCIPLES_WEB.pdf">http://www.amnesty.ie/sites/default/files/report/2012/04/PRINCIPLES_WEB.pdf</a>	This document was intended to provide some guidance regarding the requirements of Article 12. These principles adopt a ‘continuum of support approach’ which should be reflected in any capacity legislation. This ‘continuum of supports’ model is based on Bach and Kerzner’s proposals to the Ontario Law Commission for legal capacity reform and comprises three levels of support: ‘legally independent;’ ‘supported decision-making;’ ‘facilitated decision-making.’ The document clearly



		<p>outlines the role which support persons (including guardians when their role is strictly to advocate for the will and preference of the individual concerned rather than engage in substitute decision-making) could play in an Article 12-compliant system of supports and its implications for Persons with disabilities' access to justice and engagement in legal proceedings.</p>
	<p><i>Equality, Dignity and Human Rights - Does the Assisted Decision-Making (Capacity) Bill 2013 fulfil Ireland's human rights obligations under the Convention on the Rights of Persons with Disabilities?</i> October 2013. Available at <a href="http://www.nuigalway.ie/cdlp/documents/amendments_to_bill.pdf">http://www.nuigalway.ie/cdlp/documents/amendments_to_bill.pdf</a></p>	<p>Issues One and Two of this analysis contains a number of recommendations for the forthcoming legislation, addressing, for example, the role of guardians in certain situations under the system of support. According to 'Issue I highlights that 'Everyone should have the right to benefit from assisted decision-making.' Issue II underlines that 'People should have more choice and control in deciding who will assist them with making decisions.'</p>
	<p>Joint Committee on Justice, Defence and Equality: <i>Report on hearings in relation to the Scheme of the Mental Capacity Bill 2012</i>, May 2012. Available at: <a href="http://www.oireachtas.ie/parliament/media/michelle/Mental-capacity-text-REPORT-300412.pdf">http://www.oireachtas.ie/parliament/media/michelle/Mental-capacity-text-REPORT-300412.pdf</a></p>	<p>The Report clarifies the parliamentary position at the time, and by reason of the annexing of all submissions made to the Committee during the hearings, it provides an excellent comparative viewpoint of the various views of different stakeholders within the process regarding the form which legal capacity reform should take and the principles upon which such reform should be based. In particular, it outlines the diversity of opinion regarding the role of guardians in the new system.</p>
	<p>Law Reform Commission: <i>Consultation Paper on Law and the Elderly</i>. 2003. Available at <a href="http://www.lawreform.ie/fileupload/CPS%202004%20and%20older/cplawandelderly.pdf">http://www.lawreform.ie/fileupload/CPS%202004%20and%20older/cplawandelderly.pdf</a></p>	<p>The Consultation Paper addressed the need to reform the ward of court system.</p>



	Law Reform Commission: <i>Consultation Paper on Vulnerable Adults and the Law: Capacity</i> . 2005. Available at <a href="http://www.lawreform.ie/fileupload/consultation%20papers/Consultation%20Paper%20on%20Capacity.pdf">http://www.lawreform.ie/fileupload/consultation%20papers/Consultation%20Paper%20on%20Capacity.pdf</a>	The Consultation Paper addressed the need to reform the ward of court system.
	Law Reform Commission: <i>Vulnerable Adults and the Law</i> . 2006. Available at <a href="http://www.lawreform.ie/fileupload/Reports/Report%20Vulnerable%20Adults.pdf">http://www.lawreform.ie/fileupload/Reports/Report%20Vulnerable%20Adults.pdf</a>	The 2006 report addressed capacity in relation to financial and healthcare decisions as well as the right to marry. This document is extremely detailed in terms of its analysis of the current system in Ireland and the role of guardians in that system.
	Courts Service: <i>Courts Service Annual Report 2012</i> . Available at <a href="http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/87BE463114EF96FF80257BA20033953B/\$FILE/Courts%20Service%20Annual%20Report%202012.pdf">http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/87BE463114EF96FF80257BA20033953B/\$FILE/Courts%20Service%20Annual%20Report%202012.pdf</a>	The 2012 Courts Service Annual Report provides data on the operation of the current Wards of Court system.
	The Courts Service: <i>Office of Wards of Court – An Information Booklet</i> . May 2003. Available at <a href="http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/E6C1CF1ED06088A1802579050051CD90/\$FILE/Wards%20of%20court%20booklet.pdf">http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/E6C1CF1ED06088A1802579050051CD90/\$FILE/Wards%20of%20court%20booklet.pdf</a>	This is an explanatory document.
	Eilionóir Flynn: <i>Human Rights in Ireland</i> . Available at <a href="http://humanrights.ie/author/eilionoirflynn/">http://humanrights.ie/author/eilionoirflynn/</a>	The posts of Dr. Eilionoir Flynn on the website Human Rights in Ireland provide expert analysis of the process of reform in Ireland over the last number of years.
European level	Bartlett, P. (2012). <i>The United Nations Convention on the Rights of Persons with Disabilities and mental health law</i> . The Modern Law Review, 75(5), 752-778.	This paper discusses a number of flashpoints where the CRPD will require real and significant reconsideration of English mental health and mental capacity law. The CRPD introduces a new paradigm into international disability law, relying on the social model of disability. While that is no doubt a good thing, there is as yet no clear sense as to how that is to be implemented. After providing an



		introduction to the Convention, the paper considers four specific areas of mental capacity law: focusing on the provisions of the Mental Capacity Act 2005, psychiatric treatment without consent, civil detention of people with mental disabilities, and mental disability in the criminal system.
	Browning, M., Bigby, C., & Douglas, J. (2014). <i>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</i> , (ahead-of-print), 1-12	This article aims to help readers to understand the conceptual link between supported decision making and legal capacity and how this is influencing the development of practice. It examines how the concept has been defined as: a process of supporting a person with decision making; a system that affords legal status; and a means of bringing a person's will and preference to the centre of any substituted decision-making process.
	Devin, N. (2013). <i>Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities</i> . <i>The Journal of Law, Medicine &amp; Ethics</i> , 41: 792–806	The objective of this paper is to show conceptually the connection between supported decision-making and the preservation of personal autonomy for persons with intellectual disabilities. This paper discusses supported decision-making based on Bach and Kerzner's model: (a) legally independent status, (b) supported decision-making status, and (c) facilitated decision-making status. Arguments will be made based on John Stuart Mill's concept of autonomy and arguments against it using Sarah Conly's argument for paternalism.
	Dhanda, A. (2006). <i>Legal capacity in the disability rights convention: stranglehold of the past or lodestar for the future</i> . <i>Syracuse J. Int'l L. &amp; Com.</i> , 34, 429	
	Dinerstein, R. D. (2011). <i>Implementing legal capacity under Article 12 of the UN Convention</i>	





	<i>on the Rights of Persons with Disabilities: the difficult road from guardianship to supported decision-making.</i> Hum. Rts. Brief. 19, 8	
	Flynn, E., & Arstein-Kerslake, A. (2014). <i>Legislating personhood: realising the right to support in exercising legal capacity.</i> International Journal of Law in Context, 10(01), 81-104	This paper examines the regulation of 'personhood' through the granting or denying of legal capacity. It explores the development of the concept of personhood through the lens of moral and political philosophy. It highlights the problem of upholding cognition as a prerequisite for personhood or the granting of legal capacity because it results in the exclusion of people with cognitive disabilities (intellectual, psycho-social, mental disabilities, and others).
	Flynn, E. (2013). <i>Making human rights meaningful for people with disabilities: advocacy, access to justice and equality before the law.</i> The International Journal of Human Rights, 17(4), 491-510	A state-operated advocacy system acts as a mechanism for enforcing rights and can also support people with disabilities in exercising their legal capacity. This article argues that a right to an independent state-appointed advocate at domestic level is needed to realise and make meaningful the human rights to equality before the law and access to justice – focusing on the expression of these rights in the CRPD.
	Flynn, E., Arstein-Kerslake, A. (2014). <i>The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?</i> . Berkeley J. Int'l L., 32, 134-281	
	Gooding, P. (2012). <i>Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law,</i> Psychiatry, Psychology and Law, 20(3), 431-451	This article seeks to clarify the concept of supported decision-making and to consider its major implications for mental health law.
	Grant, E., & Neuhaus, R. (2012). <i>Liberty and Justice for All: The Convention on the Rights of Persons with Disabilities.</i> ILSA J. Int'l & Comp. L., 19, 347	
	Kayess, R. and French, P. (2008). <i>Out of Darkness into Light? Introducing the Convention on the Rights of Persons with</i>	This essay interrogates the intellectual antecedents of the CRPD and its continuity and discontinuity



	<i>Disabilities</i> , Human Rights Law Review, 8(1), 1-34	with 25 years of international law and its struggles with disability and human rights. It then explores the text of the CRPD, critically examining its potential contribution to the realisation of the rights of persons with disability.
	Keys M. (2009). <i>Legal Capacity Law Reform in Europe: An Urgent Challenge</i> , in Quinn & Waddington, (ed.s) European Yearbook of Disability Law, Intersentia, 2009, pp 61-91	
	Lewis, O. (2011). <i>Advancing legal capacity jurisprudence</i> , European Human Rights Law Review, 6, 700-714	
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## Annex II: Glossary of Terms

It is important to define key terms at the outset. The precise nature of guardianship systems and access to justice mechanisms differ in each of the five countries. Yet overarching models in law and policy can be identified. The following terms are drawn from the literature on disability law and international human rights and will be defined for the purposes of this research.

**‘Access to justice’** is a ‘broad concept, encompassing people’s effective access to the systems, procedures, information, and locations used in the administration of justice. Persons who feel wronged or mistreated in some way usually turn to their country’s justice system. In addition, persons may be called upon to participate in the justice system, for example, as witnesses or as jurors in a trial. Unfortunately, persons with disabilities have often been denied fair and equal treatment before courts, tribunals, and other bodies that make up the justice system in their country because they have faced barriers to their access. Such barriers not only limit the ability of persons with disabilities to use the justice system, they also limit their contributions to the administration of justice.’

**‘Communication’** in the terms of the CRPD ‘includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.’

The term **‘intellectual disability’** is variously defined. The UN CRPD does not seek to define disability in totality but states that disability ‘includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’ Individuals who have the label of an intellectual disability can and should be described in many other ways including, friend, neighbor, relative, parent, colleague, community member, employee, employer and parent. They may have difficulty with certain cognitive skills, although this varies greatly among individuals. We adopt a progressive understanding that ability-disability is a continuum that all human beings exist on at various stages in our lives, where disability is an infinitely various but universal feature of the human condition. In keeping with international human rights law, as well as the standards set by leading advocacy organizations for people with intellectual disabilities, such as Inclusion Europe, we do not wish to define intellectual disability prescriptively. After all, definitions may vary in different countries and we wish to avoid being over- and under-inclusive in our use of the term. Instead, for the purposes of this research we understand intellectual disability in the broad sense of the term as including those who may require intensive support in almost all aspects of their lives, and those who require support only in some areas, such as with financial administration. In other words, the AJuPID project draws on a definition of intellectual disability that encompasses a wide spectrum including people with a range of complex, profound, or relatively slight intellectual impairments and disabilities.

**‘Legal capacity’** refers to both a person’s legal standing (legal personality) but also his or her ability to act on such legal standing (legal agency). An oft-used example to illustrate this definition is

94



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voting. A person may hold a formal right to vote on an equal basis with others (their legal personality is upheld). Yet a lack of reasonable accommodation – such as ramps to enter polling stations, or plain language guides – may mean that a person cannot exercise their right to vote on an equal basis with others (their legal agency is denied). Both elements – legal personality and legal agency – are required in order that a person has legal capacity on an equal basis with others.

**‘Mental capacity’** is a concept used in ethics and law which asks that someone demonstrates ‘independent’ capacity to consider a range of options when deciding, to consider the consequences of different options, and to communicate a choice. When a person is deemed to lack mental capacity a substituted decision-maker is typically appointed by courts to make decisions on his or her behalf – typically using a ‘best interests’ standard to guide decision-making.

**‘Procedural accommodation’** is a term used in Article 13(1) to refer to reasonable accommodations provided in justice systems to ensure ‘persons with disabilities who intervene in the judicial system can do it as subjects of rights and not as objects of protection.’

**Reasonable accommodation’** refers to necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. According to the terms of the CRPD, ‘discrimination on the basis of disability’ (...) includes all forms of discrimination, including denial of reasonable accommodation.’

**‘Substituted decision-making’** is a term used in international disability law to refer to the authorized appointment of someone to make a decision on behalf of a person who is deemed to lack the mental capacity to make a decision for him or herself. ‘Substituted decision-making’ typically occurs regarding decisions related to healthcare, lifestyle or financial issues, and are typically made according to what is perceived to be in a person’s ‘best interests.’ The CRPD Committee defines ‘substituted decision-making regimes’ as follows:

Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.

**‘Supported decision-making’** is one type of support to exercise legal capacity. Supported decision-making refers to a decision made by a person, on his or her behalf, with support from others in order to exercise his or her legal capacity.

A **‘supported decision-making regime’** is a term used by the CRPD Committee to describe the overarching model of support in line with Article 12 of the CRPD. It includes various support options which give primacy to a person’s will and preferences. Such a regime should provide protection for



all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.). While supported decision-making regimes can take many forms, they should all incorporate certain key provisions to ensure compliance with article 12 of the CRPD, including being available to all, even those with complex communication and intensive support needs, and being ‘based on the will and preference of the person, not on what is perceived as being in his or her objective best interests.’ The regime should include readily available and accessible supports, including facilitating support for ‘people who are isolated and may not have access to naturally occurring supports in the community,’ as well as the right to refuse such supports. (A more complete definition of a ‘supported decision-making regime can be read in the CRPD Committee’s first General Comment).

**‘Support to exercise legal capacity’** refers to the obligation on States Parties set out in Article 12(3) of the CRPD so that persons with disabilities can exercise their legal capacity on an equal basis with others. ‘Support’ is not specified in Article 12(3) but according to the CRPD Committee it ‘encompasses both informal and formal support arrangements, of varying types and intensity.’ Hence, support to exercise legal capacity is considerably broad, and could include personal advocacy, plain language aids in court proceedings, accessible education, and so on.























### Annex III: Guiding Principles Table

The table on the following page depicts the elements of the two key international human rights considered in this project—Article 12 CRPD (right to equal recognition before the law) and Article 13 CRPD (access to justice). The table refers to elements that were defined in the guiding principles of this report. The principles help to gain a better idea of what these rights mean in practice, and help to identify steps along the way to their realization. The rights refer specifically to the rights of adults with intellectual disabilities. The tables include recommendations of a *very general* nature, though we have sought to refer to specific areas of concern or specific examples of promising practices emerging in each country. They are based on the evaluative expert opinions of researchers and AJuPID members.



**Table 1.1**

A. 12 & 13 Elements	Finland	Recommendation	Bulgaria	Recommendation	Ireland	Recommendations
i – legal capacity on equal basis w others		Finland is initiating supported decision-making measures in addition to existing alternatives to guardianship. These efforts should include broad-based national supported decision-making legislation and a suite of support practices to this end.  Gaps remain in ensuring access to justice and equality before the law for this group. We therefore recommend: judicial training on the support needs and human rights of persons with intellectual disabilities and the re-enforcement of procedural accommodations, such as courtroom videolink.		Bulgaria is making considerable progress at the regional level by initiating supported decision-making pilot programs. This active step toward implementation of the provisions of A12 CRPD is unique in Europe and should be used as a launching site for similar law, policy, and practice throughout Europe.  There remain gaps in Bulgarian law in ensuring access to justice for adults with intellectual disability. There are a number of areas of concern, but based on pressing need we recommend: the introduction of judicial training, introduction of intermediaries, and the removal of degrading and outdated language to describe people with disabilities in law.		The development of the Assisted Decision-Making (Capacity) Bill 2013 in Ireland is a promising example of efforts to introduce supported decision-making and equal recognition before the law for adults with intellectual disabilities (and people with disabilities generally). It should be used as an example of progressive law that enables access to justice for people with intellectual disabilities.  However, the Bill maintains a discriminatory assessment of mental capacity and should instead be moved to a focus on choice, and on the wishes and preferences of the
ii – enjoyment of legal capacity in access to justice						
iii – access to support in exercise of legal capacity, incl. right to access to justice						
iv – support measures respecting rights						
v – effective access to justice ensured						
vi - procedural and age-appropriate accommodations ensured						

































vii - enabled to take part in legal proceedings						individual. It is recommended that as well as amending the Bill, a comprehensive audit of laws relating to legal capacity and access to justice be undertaken to address gaps.
Viii - enabled to take part in proceedings directly and indirectly						
ix - provided with access to information and communication						
x - judiciary trained about their obligation to respect rights of PwID.						

Table 1.2

A. 12 & 13 Elements	France	Recommendations	Hungary	Recommendations
i – legal capacity on equal basis w others		<p>The use of family councils in France provides a novel practice with potential application in supporting adults with intellectual disability to exercise their legal capacity and access justice elsewhere.</p> <p>It is recommended that France builds on the family council model, which rightly identifies the interdependence of all adults with their family and other supporters, to develop the model without requiring a denial of legal capacity based on an assessment of mental incapacity. We are concerned that France does not appear to be taking steps to introduce broad-based supported decision-making legislation, and we recommend this to occur. These steps could include introduce supported decision-making trials for people with disabilities and others (not guardians). We also recommend introducing training of the judiciary on disability rights, and introduce procedural accommodations. While there is considerable training for guardians, we recommend that other support persons are ensured education and training for fulfilling their role, including by emphasizing the will and preferences of the key person.</p>		<p>Hungary has initiated supported decision-making practices and has created a role for professional supporters and preliminary legal statements to support adults with intellectual disability to exercise legal capacity and access justice.</p> <p>Yet Hungary still has unacceptably high rates of partial and plenary guardianship, and a number of barriers to access to justice remain. Plenary guardianship must be abolished immediately. Further, although good practice in supported decision-making exist, there is a strong need to implement supported decision-making initiatives, to build upon them so that they are accessible to Hungarians with intellectual disability, and to <i>ensure that the provision of supported decision-making is separated from guardianship</i> – at present the distinction between supporters and guardians is not clear enough. In the specific realm of access to justice it is also recommended that Hungary bolster its efforts to ensure the possibility for direct testimony of adults with disabilities. Finally, adults with intellectual disability should have legal standing regardless of their mental capacity status.</p>
ii – enjoyment of legal capacity in access to justice				
iii – access to support in exercise of legal capacity incl. right to access to justice				
iv – support measures respecting rights				
v – effective access to justice ensured				
vi - procedural and age-appropriate accommodations ensured				
vii - enabled to take part in legal proceedings				
Viii - enabled to take part in proceedings directly and indirectly				
ix - provided with access to information and communication				
x - judiciary trained about their obligation to respect rights of PwID.				

## **Annex IV: Template for data gathering from partner countries**

### **Access to Justice for persons with Intellectual Disabilities (AJuPID)**

#### **Workstream 1: Research**

#### **Activity 2: Comparison of legal protection laws and models Activity**

#### **Template for data gathering from partner countries**

1. Please read attached country reports from ANED (DOTCOM) and FRA – and provide any new information or updates (from 2010) on the following issues:

Any currently proposed reforms to the systems of legal guardianship (including both plenary and partial guardianship) – especially on the following:

- j) Procedures for challenging the appointments of guardians, specific decisions of guardians, or review/removal of guardians
  - k) introduction of less restrictive alternatives to guardianship to support individuals in the exercise of their legal capacity (without removing their legal capacity)
  - l) data on numbers of cases where individuals
    - have successfully and unsuccessfully challenged the appointment of guardians
    - had guardians removed (comparing to failure of removal of guardians) and
    - had legal capacity restored (comparing to failure of restoration of legal capacity).
2. Please provide information on the participation of people with intellectual disabilities in the justice system and provide any updates from existing reports on the following issues in civil and administrative proceedings – with particular reference to the relevant legal proceedings (statutory review of guardianship, revocation of guardianship, property, choice of where and with whom to live) wherever possible:

101



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- k) law, policy and practice on persons with intellectual disabilities rights' to seek legal assistance (including eligibility for free legal aid) and to directly instruct legal representation
- l) legal standing of persons with intellectual disabilities to initiate a court or tribunal action (in civil and administrative cases) or to make complaints to dispute resolution forums, including arbitration and mediation mechanisms, and recourse to domestic complaints mechanisms of last resort, including the Ombudsman/NHRI
- m) legal mechanisms or practices in the justice system which require judges to personally meet with people with intellectual disabilities who are the subject of a case and regulations for this process
- n) rules of evidence and procedure which enable people with disabilities to give direct testimony in court – and any regulations or reported cases involving the use of interpreters, or other communication supports – including augmented and alternative communication, facilitated communication, or total communication
- o) procedural accommodations which enable persons with intellectual disabilities to participate in court proceedings – including the design of court rooms and proceedings, and the use of video testimony
- p) the role of intermediaries in communicating the views of persons with intellectual disabilities to the court and procedures or regulations regarding who can be an intermediary (parent, guardian, advocate, lawyer, litigation guardian/guardian ad litem, social worker, other professional, other family member or friend) and what the scope of their role is (ie. only to present the person's views to the court or to also suggest to the court what the possible outcome should be in the case, based on the individual's 'best interests' or other criteria).
- q) the role of guardians (if any) in initiating procedures, challenging court and administrative bodies' decisions on behalf of or together with persons with intellectual disabilities placed under guardianship – and how commonly such procedures are initiated, and the outcomes, if known, of such procedures
- r) any existing or proposed elements of compulsory training for guardians and/or support persons on the rights of persons with intellectual disabilities and effective communication techniques



- s) any existing or proposed elements of compulsory professional training for officials in the justice system (lawyers, judges, clerks, notaries, etc.) on the rights of persons with intellectual disabilities and effective communication techniques.

