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Legal Capacity and Supported Decision-Making: Lessons and Outcomes of Pilot Projects Implementing Article 12 of the United Nations Convention on the Rights of Persons with Disabilities

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Abstract

The present thesis explores the notion of legal capacity and supported decision-making as enshrined in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. The thesis begins by outlining the policy context, how guardianship has been progressively criticised and reformed and how the notion of supported decision-making gradually expanded until the genesis of Article 12. A narrative review explores how scholars have grappled with the meaning of supported decision-making and attempted to define what it means concretely. Many questions remain largely unanswered and there is a need for guidance on how Article 12 can be implemented in practice, how to operationalise Article 12 and make sure that supported decision-making is also available to people with high support needs. This review is followed by an analysis of four pilot studies that were previously evaluated and findings made publicly available. It concludes that the existing evaluations do not provide answers in sufficient detail to allow the construction of a tool to analyse the implementation of Article 12 in practice. The second part of this thesis thus responds to the gaps identified in the previous literature and evaluations. To do so it explores the aims, methodology, outcomes and lessons learnt in six pilot projects seeking to implement supported decision-making in different parts of the world. An analytical framework, based on the findings of previously reviewed literature and theory, delineates nine domains that serve to analyse the impact and outcomes of each pilot project. Detailed analysis of the six pilot projects concludes that, although the pilot projects go some way towards operationalising and implementing Article 12, there remain many gaps in this respect. This thesis concludes with the discussion of the findings and the consideration of implications for research, policy development and new pilot projects to achieve a real culture change. Several structural barriers and challenges need to be solved to advance Article 12 implementation. Resistance to changes, gaps in policy and practice, lack of infrastructure remain the principal challenges ahead. Successful implementation of Article 12 implies to encourage a culture of change, working on law, policy, practice and training programmes in synergies.

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Introduction

The adoption of the United Nations Convention on the Rights of People with Disabilities (hereinafter CRPD) in December 2006 is a landmark in disability policy (Kayess and French, 2008). Equal recognition before the law, as set out in Article 12 of the CRPD, lies at the heart of this revolution introducing a new paradigm of universal legal capacity that cannot be limited on the ground of disability or mental capacity (Series and Nilsson, 2018; CRPD Committee, 2014). Article 12 embraces a model based on different forms of supports, respectful of the will and preferences of the person, as "*independence and personal autonomy is not about being able to do everything on your own, but having control of your life and the possibility to make decisions and have them respected by others*.", (Commissioner for Human Rights, 2012). With the recognition of a universal right to legal capacity comes the claim to equality and non-discrimination, the end of an era of systematic loss of human rights, incapacitation and guardianship laws (CRPD Committee, 2014).

Legal capacity can be described in various ways, but in essence it means that a person is subject to the law and a bearer of rights and obligations. It means that the person can make binding decisions, by entering, creating, modifying or ending legal relationships. Legal capacity means more than having the right to take decisions- it recognises that decisions and choices are part of who human beings are (Keys, 2009; Commissioner for Human Rights, 2012).

The right to make one's own decisions, enjoying autonomy and self-determination have traditionally been denied to people with disabilities, especially those with intellectual and psychosocial disabilities, because they have been routinely deprived of legal capacity and put under guardianship (Booth Glen, 2012; Keys, 2009; MDAC, 2013; FRA, 2013; Inclusion International, 2014; Degener, 2017). Guardianship is a legal mechanism whereby an authority deprives a person of the power to make and act on some or all decisions, and grants that power to another individual or sometimes an entity (e.g. appointed through court decision, often called legal guardian), who makes decisions on behalf of the concerned person, based on the finding that this person lacks capacity (among other reasons because of the person's disability). Guardianship and other similar mechanisms can be grouped in the so-called substituted decision-making model, because the decision-making power is vested in another person. People under guardianship are denied the freedom to make decisions and often have no control over their own lives, no opportunities to participate in society, with guardianship effectively resulting in their "civil death" (MDAC, 2007, 2008; Keys, 2009).

It is estimated that about one million people within the Council of Europe region are deprived of their legal capacity (MDAC, 2013, Commissioner for Human Rights, 2012). And a large number of those are also living in large residential institutions (Keys, 2009). The number of people living in institutions has not changed substantially in recent years (Šiška and Beadle-Brown, 2020). Data about the number of persons under guardianship is not always accessible, as the government may not hold such information. These numbers vary greatly from country to country. The Mental Disability Advocacy Centre, an international non-profit organisation, reported in a research study published in 2013 that Ireland had 48 people under guardianship per 100,000 of the population; Bulgaria 100 per 100,000, Latvia 106, Moldova 152, Poland 158, and Lithuania 167. Figures are even higher for the Czech Republic: 317, Croatia: 410 and Hungary with 596 guardianships per 100,000 population[1] (MDAC, 2013). The *Access to Justice for Persons with Intellectual Disabilities* project found comparable figures for five European countries: the lowest number is Finland with 32 persons under guardianship per 100,000 of the population; Ireland 51; Bulgaria 97 France 99 and Hungary 586 (AJuPID, 2015).

Disability organisations and other human rights organisations regard guardianship as encroaching on the liberties of citizens and deprivation of legal capacity the cause for human rights abuses (Minkowitz, 2007; Commissioner for Human Rights, 2012; MDAC 2007; Kanter and Tolub, 2017; Flynn and Arstein-Kerslake 2014b). For example, the results of the fieldwork conducted by the European Union Fundamental Rights agency in 2010-2011 with more than 200 persons with intellectual and psychosocial disabilities described how guardianship and other substituted decision-making models affect their lives. The report reveals the lack of participation of people in the proceedings, the lack of understanding of the role and the limits of the power of the guardians, and the lack of participation in decisions such as placement in hospital or medical treatment (FRA, 2013). Another important issue is the loss of control over personal finances (FRA, 2013). This relates to important decisions such as inheritance but also daily financial decisions. The report also points out the fact that the role of family members and guardians is often blurred. Only a few interviewees reported that their supporters help them sufficiently. They identified as crucial elements the length of time spent in person to support them, and also the opportunity to be heard and have a voice (FRA, 2013).

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[1] See the graph on p. 22 in MDAC, 2013, Legal Capacity in Europe, A Call to Action to Governments and to the EU available at https://www.mdac.org/en/resources/legal-capacity-europe-call-action-governments-and-eu (last accessed 4/8/2021)

More striking is also the resignation of people with disabilities in fighting for their rights. They not only reported about the difficulty in lodging a complaint, but also about the overwhelming nature of the processes, and the fact they rarely have control over their complaint; finally, they do not believe that their complaints would be upheld (FRA, 2013).

The report also highlights the informal restrictions on decision-making. Formal guardianship measures illustrate only part of the problem, as people with disabilities often face restrictions of legal capacity in practice due to mainstream social attitudes, as they are seen as incapable by society (Human Rights Council, 2015, Inclusion International, 2014). They have no opportunity to make choices because of paternalistic attitudes, overprotection and low expectations (FRA, 2013; Inclusion International, 2014). They may not be given full information about their health situation or finances, or about available options or choices, because information has been preselected for them (FRA, 2013; Inclusion International, 2014). Self-advocates identified as the most common barriers: the fear of making decisions or making a “bad” decision, as they lack confidence and the lack of empowerment or training to make decisions (Inclusion International, 2014).

In contrast, Article 12 recognises the right to make decisions for oneself (Devi, 2013), by granting to people with disabilities the right to legal capacity on an equal basis with others, that is with support in exercising their legal capacity, such support being respectful of the will and preferences of the person. The term supported decision-making is often used in relation to this model of Article 12 to describe a process by which persons with disabilities receive assistance to make legally enforceable decisions by themselves (in contrast to the substituted decision-making model where the decision is taken by another person).

The Committee on the Rights of Persons with Disabilities (the CRPD Committee), a body of independent experts responsible for monitoring the implementation of the CRPD, in its interpretation of Article 12, calls for the end of systematic deprivation of legal capacity and prohibits all forms of substituted decision-making. The Committee defined it as systems where *“(i) legal capacity is removed from a person, even if this is 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; and (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*“ (CRPD, 2014). Although the Committee’s position is contested in the literature and by States Parties (Series and Nilsson, 2018), it states that legal capacity can no longer be removed or limited on the basis of disability or mental incapacity (CRPD, 2014). And it calls for the development of supported decision-making alternatives, which give primacy to a person's will and preferences.

However, more than a decade after the ratification of the CRPD, Article 12 continues to generate heated discussions, because of its ambiguity, complexity and far-reaching impact. Factors such as the growing interest in the protection of vulnerable adults, the increasing number of people with impaired capacity, especially in the older population, disability as a human rights issue and the ratification of the CRPD have pushed the issue of legal capacity high on the political agenda of international and European organisations in the past decade (Human Rights Council, 2017; FRA, 2013; IDA, 2010). But there is still a lack of understanding of Article 12 (Degener, 2017; CRPD, 2014) and the CRPD Committee has been repeatedly saying that no country complies with its provisions. This thesis aims to achieve a better understanding the meaning of Article 12, to identify key elements of substituted decision-making as compared to those of supported decision-making and propose steps for implementing Article 12. It does so through examining CRPD inspired pilot initiatives in different countries across the globe that focus on legal capacity and supported decision-making. It examines both legal and policy aspects of Article 12 as well as social work and community involvement. As will be argued in this thesis each of these elements is essential. The thesis aims to answer the following questions: What criteria and characteristics should models of support fulfil to be compatible with Article 12? What lessons have we learnt from the pilot projects? How pilot project outcomes contribute to the advancement of implementation of Article 12?

To understand the challenges and difficulties in making Article 12 a reality and explain the trends that characterise current legal capacity reforms and initiatives, it is useful to take a brief look back at the history of guardianship and the genesis of the CRPD.

Historical perspective on guardianship and the human rights of people with disabilities

Blankmann's review of Western laws on guardianship shows the roots of guardianship in Old Roman Law and its considerable influence on Civil Codes which recently had or still have measures reminiscent of the *cura furiosi* (Sherman, 1913; Blankmann, 1997). This cura is mentioned in Lex XII Tabularum, which is dated around 450/451 BC. Table V of the Twelve Tables, 7a, reads: *Si furiosus escit, adgnatum gentiliumque in eo pecuniaque eius potestas esto*. Or in English: "a mad person is placed under the guardianship of his family members with his person and money" (Blankman, 1997; Stelma-Roorda, 2019, 1913). It protected the family assets so, to that end, the *furiosus* was incapacitated; the “tutor” or “guardian” being a male to whom protective powers were granted.

For thousands of years this model survived in many West European countries and also world-wide (Sherman, 1913; Blankman, 1997) including countries where Civil Codes have been influenced by European colonialism (Booth Glen, 2012). Until the 1960s this status-based approach and model (disability equals incapacity) was the only answer to the issue of capacity of people with mental impairment. The human rights of people with disabilities emerged in the 1950s and 1960s, moving from the status of recipients of welfare and services, after War World II and the development of instruments, especially the Universal Declaration of Human Rights in 1948 and then the International Covenant on Civil and Political Rights (ICCPR) as well as the International Covenant on Economic, Social and Cultural Rights (ICESCR). However, none of the equality clauses of any of the three instruments (UDHR, ICCPR or ICESCR) mentions persons with a disability as a protected category.

The binary model that is a person had, or did not have capacity, then evolved to a diagnosis driven model, with the development of medicine (Booth Glen, 2012). Some nuances based on medical diagnosis were introduced in the incapacitation process, giving a justification for the intervention on the part of judges, who decided about protection measures. Procedural protections were few and the incapacitation procedure resulted, and still results, in deprivation of rights including the rights to contract, to choose a place of living, have a job, marry, establish a family, manage their own money or property, the right to vote, a denial affecting most areas of life of people with intellectual and psychosocial disabilities (Human Rights Council, 2017; Inclusion International, 2014; MDAC, 2013; Booth Glen, 2012).

Historically, there have been different ways to look at the experiences of people with disabilities which are reflected in international instruments. As Kayess and French argue, the most influential model is the medical model – people with disabilities are seen as victims of great misfortune, socially dead off and living with a condition that will forever limit their activities (Kayess and French, 2008). The focus of this model is therefore on the impairment and “*the provision of cure, treatment, care and protection to change the person so that they may be assimilated to the social norm“* (Kayess and French, 2008). By contrast the social model locates the experience of disability in the social environment, rather than impairment. This model implies to remove the social and physical barriers to allow participation and inclusion of persons with disabilities. The text of the CRPD further embeds a ‘paradigm shift’ away from a social welfare response to disability to a rights-based approach (MacKay, 2007). The CRPD conceptualised this paradigm shift by rejecting the ‘view of persons with disabilities as objects of charity,’ and affirming persons with disabilities as ‘subjects of rights,’ (Arbour, 2006).

The 1970s marked the first decade of human rights instruments dealing with disabilities (the 1971 Declaration on the Rights of Mentally Retarded Persons, and the 1975 Declaration on the Rights of the Disabled Person). However, they were all non-binding and embedded in the medical model. The 1971 declaration nonetheless represented a significant step in having people with disabilities recognised as having human rights (Kayess and French, 2008; UN ENABLE, 2003-2004). This movement opened the debate about legal incapacity and subsequently called for reforms (Blankmann, 1997; Stelma-Roorda, 2019). In addition, ethical questions, related to medical care and consent to treatment for example, became another area of interest whereas before mainly financial matters were looked at.

In 1991, the United Nations General Assembly adopted the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care: while the principle of substituted decision-making was still not questioned[2], the appointment of a representative should be accompanied by several safeguards: a fair hearing by an independent and impartial tribunal, free legal counselling/aid for the person, the absence of conflict of interest, regular reviews and right to appeal. [3]

The United Nations Decade of Persons with Disabilities (1983-1992) ended with another non-binding instrument, despite early views pushing for the adoption of a Convention (Kayess and French, 2008). “The Standard Rules on Equalisation of Opportunities for Persons with Disabilities” adopted in 1993 establishes that discriminatory provisions (including with respect to sexual relationships, marriage and parenthood) against persons with disabilities must be eliminated but there is no specific mention of discrimination in relation to guardianship laws. People with intellectual and psychosocial disabilities were still considered as specific vulnerable groups, assuming that 'protections' such as guardianship was needed.

In summary, little change for very long time in the context of legal capacity and the way of thinking about autonomy of decision-making of people with disabilities.

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[2] reform processes already started in some part of the world :see the history of the reform of legal capacity in British Columbia presented in a template created by Nidus, a non-profit organisation, in April 2010 – unpublished document by Nidus

[3] Paragraph 6 of principle 2 of the Principles for the protection of persons with mental illness and the improvement of mental health care available at https://www.who.int/mental_health/policy/en/UN_Resolution_on_protection_of_persons_with_mental_illness.pdf (last accessed 27/7/2021)

The mandate for an international Convention came with the claim for the UN Millennium Development Goals (MDGs) in 2000. The perspective of persons with disabilities as the "poorest of the poor" worldwide created a large consensus for the adoption a new binding instrument (Kayess and French, 2008). It was clear by then that generic sets of rights do not adequately capture the situation of members of groups who face systematic discrimination and disadvantages (Bantekas & Oette, 2016). This resulted in the drafting and adoption of the first human rights Convention of the 21st century in only five years (December 2001[4] – December 2006[5]). And in its Article 12, the Convention addresses the issue of decision-making of people with disabilities and recognises the right to legal capacity. Since its drafting, however, Article 12 has remained highly controversial.

Protection versus autonomy: the tensions around Article 12

The *travaux preparatoires* and the unprecedented participation of people with disabilities in the CRPD negotiations (including disability activists and disabled people's organisations DPOs) (Kayess and French, 2008) show that during the sessions of the ad-hoc Committee, heated debates arose between antagonistic positions, protection and paternalism against participation and autonomy (Dhanda, 2007). The genesis of Article 12 will be explored in more depth in Chapter 1. In short, to guarantee its adoption and subsequent ratification, DPOs had to accept the ambiguity about whether Article 12 permits or prohibits substituted decision-making (Series and Nilsson, 2018).

Tensions about Article 12 interpretations can be seen through the number of reservations or interpretive declarations adopted at the CRPD ratification: ten countries stated that they understand Article 12 to permit substituted decision-making and restrictions of legal capacity.[6]

Signs of these tensions can also be recognised in further activities of the CRPD Committee: the concluding observations following States Parties reports repeatedly state that they have to "*replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will, and preferences*[7]." The CRPD Committee has chosen Article 12 for its first

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[4] On 19 December 2001, the UN General Assembly established an Ad Hoc Committee "to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities (resolution 56/168)

[5] On 13 December 2006, the Plenary of the General Assembly adopted by consensus the CRPD and its optional protocol

[6] https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en#EndDec In addition, by a reservation on art. 29, some countries interpret Article 12 as in compliance with their legislation.

[7] See Concluding observations on Article 12 in the document gathered by IDA – very similar sentences can be read in numerous concluding observations:

general comment, justifying this decision by the fact that "*there is a general misunderstanding of the exact scope of the obligations of States Parties under Article 12*" and "*that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making*" (CRPD Committee, 2014). In parallel, the UN Special Rapporteur on the rights of persons with disabilities identified law reforms processes (some of which may have been aborted) in at least 32 countries (Human Rights Council, 2017).

In reaction, some countries have expressed concerns regarding the interpretation of Article 12 set out in the General Comment No. 1 reasserting that the Convention allows for restrictions of legal capacity in certain circumstances (FRA, 2013; Martin et al, 2016). The medical professions did not welcome the CRPD Committee's interpretation of Article 12 and expressed concern about the confusion of the text and the implications of the General Comment (Series and Nilsson, 2018; Freeman et al., 2015; Dawson, 2015; Appelbaum, 2016).

These tensions also show that more clarification is needed to give a clear substance to the terms supported decision-making and substituted decision-making, to better guide reform efforts. In addition, since its adoption, Article 12 has too often been dealt with as a technical problem, to be mainly dealt with by a law reform. But Article 12's impact on the other rights in the Convention needs to be considered with the realisation of many rights[8] and it should also be anchored in the "General Principles" of the CRPD, mainly the respect for *individual autonomy* and self-determination (Article 3(a)). The CRPD did not create a new right to autonomy (Megret, 2008) – but the autonomy of people with disabilities is listed as one of the Convention's "General Principles" and is also echoed in the body of the text. Necessary reforms to comply with Article 12 should also take into consideration these General Principles specifically the principle of autonomy.

Article 12 is indeed also characteristic of the debate around the pluralisation of human rights. Several authors have affirmed that the Convention did not create new rights (see for example Kayess and French, 2008), and that was also the mandate of the ad-hoc Committee (Schultze, 2010). But Article 12 obliges States to take measures to ensure people with disabilities can exercise legal capacity, thus exercise their autonomy. This claim for autonomy, which is inherent to the CRPD, nuances this idea that the Convention did not create new rights. To overcome this contradiction, Megret shows that there is a very subtle

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https://www.internationaldisabilityalliance.org/resources/compilation-crpd-committee%E2%80%99s-concluding-observations (last accessed 27/10/2021)

[8] See Articles 13, 19, 14, 15 16, 17, 23, 25 and 29.

mix of old and new rights (Megret, 2008). First, the Convention *reaffirms* (legal capacity as in 12(1) or with "appropriate and effective safeguards to prevent abuse in accordance with international human rights law"), then *reformulates* (as in 12(2) – all areas of life), *extends* existing rights but also *innovates* (as in 12(3)). The right to legal capacity is innovated here with the specific experience of people with disabilities and calls for specific measures to exercise legal capacity. Megret argues in that sense that *"there is a dimension of the experience of specific groups that is inherent to them and which almost requires the creation of new rights"* (Megret, 2008). One can argue that support to exercise legal capacity implies "innovation".

Article 12 is seen as an essential aspect to implement the Convention, but it is also the one which constantly stirs debate and raises most unanswered questions. Policy documents and academic articles highlight the numerous points of non-compliance between national legal frameworks and the CRPD provisions. But because of the tensions between the different interpretations of Article 12, there is no clear statement that it implies to innovate on legal capacity. In the past decade, the idea that universal legal capacity is not only about legal reform and removing legal barriers has made progress. But embracing the new paradigm shift - and implementing it in practice, is so far largely considered a utopia.

Methodology and thesis overall structure

This thesis therefore explores pilot projects' contributions and outcomes to better define and implement Article 12, focusing on the innovative part of the right to legal capacity. There are several reasons to look at pilot initiatives. First of all, it is often mentioned as a key step in the operationalisation of supported decision-making, to provide valuable sources of information and input for policy makers and law reforms (Human Rights Council, 2017; Inclusion International, 2014). Secondly, previous research focuses on theoretical debates around Article 12, with little attention given to the pilot projects and what can be learned from them. Another motivation is that the author of this thesis was herself involved in the design and the realisation of one pilot project.

To analyse the findings of pilot projects, a two-step approach was chosen. First, the focus was on externally evaluated pilot projects. At the beginning of this work, only four projects had been evaluated. For each evaluated pilot project, the evaluation reports and other available project material have been collected. Content analysis of the reports has been used to compare and contrast the methodologies and findings from the pilot projects as well as the limitations of both the evaluations and the pilot projects themselves. The limited and short-term outcomes and the lack of common evaluation features did not provide sufficient material for the evaluation of other pilot projects. Therefore, in a second phase, six other pilot projects have been selected for an analysis based on a framework developed for the purpose of this research.

This framework to analyse the impact and the outcomes of pilot projects has then been designed, taking into account all the necessary levels to create a system of supported decision-making (from the individual to the state level) based on the right to universal legal capacity. The framework includes nine domains of interest to gather data from all the levels, collating information from the legal, policy and social sciences fields. Six pilot projects have then been screened through that framework. Interviews with pilot project leaders, legal and policy documents as well as practice guidance and educational or awareness-raising material for decision-makers and supporters have been reported and analysed. Inspiring practices and the implications for the implementation of Article 12 are then discussed.

This thesis looks at how pilot projects constitute a tool to implement Article 12, find innovative ways to balance self-determination and rights with appropriated safeguards, while bringing together several professions not necessarily previously working together. Exploring how to create bridges between the social and legal fields is part of this implementation process. This is why this research looks into the legal and policy field as well social sciences to comprehend the implementation of Article 12 from a complex perspective. However, this research does not aim to conduct a comprehensive legal analysis of Article 12 – its text is analysed only from an international law perspective, not in the context of national legislations.

Because the terminology is different in each jurisdiction, the present work uses guardianship as a synonym of substituted decision-making; other words are used when referring to legal provisions in specific jurisdictions. In the spirit of Article 12, the terms used throughout this work to designate a person who needs support for decision-making will be “decision-maker” and a person who provides this support, “supporter”. Other words are used only when they refer to a specific historical or geographical context.

This thesis has two parts. The first three chapters provide an overview of the existing knowledge about Article 12 and supported decision-making. Chapter 1 explores the policy and legal developments in the field of adult protection and supported decision-making before and after the adoption of the CRPD, in several countries. It illustrates the trends in the legal reforms but shows the absence of realisation of the “paradigm shift”. Chapter 2 looks at the literature post CRPD and research findings about the meaning of Article 12 and supported decision-making. It explores the moral foundations of Article 12, the multiple aspects of supported decision-making and the lack of empirical and practical research in the field. It points at the numerous questions still to be answered. Chapter 3 presents the findings from four pilot studies that were previously evaluated and findings made publicly available. The chapter explores the methods used, the outcomes of the projects and concludes that the existing evaluations do not provide answers in sufficient detail to allow the construction of a tool to analyse the implementation of Article 12 in practice.

The second part of this thesis responds to the gaps identified in the previous literature and evaluations. To do so it explores the aims, methodology, outcomes and lessons learnt in six pilot projects seeking to implement supported decision-making in different parts of the world but not yet formally evaluated. There is a particular focus on how these pilot projects can help us understand how to operationalise Article 12 and how to deliver implementation in practice. Chapter 4 presents the analytical framework created for this purpose. It is based on the findings of previous literature and theory reviewed in the previous chapters. This framework takes into account different levels of operationalisation (micro, mezzo and macro) and delineates nine domains that will serve to analyse the impact and outcomes of each pilot project. Finally chapter 4 sets out the research questions for the evaluation of the pilot projects. Chapter 5 describes the methods of data collection and data analysis through the framework. Chapter 6 introduces each of the selected pilot projects, their national context, and the elements that are important to understand before applying the framework of analysis (i.e. the aim, participants and project material available for analysis). Chapter 7 presents the detailed analysis of the six pilot projects through the nine domains of the framework, and concludes that, although the pilot projects go some way towards operationalising and implementing Article 12, there remain many gaps in this respect. Chapter 8 presents a synthesis of these positive contributions to the implementation of Article 12 and these gaps. It also looks into emerging issues raised by the pilot projects analysis, highlighting the structural barriers and challenges to be solved to advance Article 12 implementation. The final chapter 9 discusses the main findings. Pilot projects show that many aspects of supported decision-making are feasible and have a positive impact on people with disabilities. Important accomplishments in law reforms and implementation, in producing and delivering training courses or material for supporters and decision-makers, in developing advocacy strategies and networks, in campaigning about supported decision-making were identified. Resistance to changes, gaps in policy and practice, lack of infrastructure remain the main challenges ahead. Chapter 9 then formulates concrete recommendations for future research, policy development and new pilot projects to achieve a real culture change.

1 Policy Context

The introduction presented the international development of human rights of people with disabilities, which culminated in the drafting of the CRPD and the recognition of the right to universal legal capacity for all. This chapter looks at the national policy context in different parts of the world from a recent historical perspective. The situation in different jurisdictions echoes the tensions about Article 12 interpretations mentioned earlier. The first section explores the growing criticism against guardianship and the early reform efforts. The reforms which happened before the adoption of the CRPD are described in the second part of this chapter. The third section explores the genesis of Article 12, its influences and compromises. The law reforms post CRPD are presented in the last section. It is not the purpose here to detail all the different reforms in each jurisdiction, but just to briefly pinpoint the main issues at stake when reforming guardianship laws and introducing supported decision-making in the legislation, and to highlight unresolved questions. These policy developments and law reforms have influenced the understanding of Article 12 CRPD and have served as points of references for pilot initiatives and further reflections.

1.1 Growing criticism and early reform efforts of guardianship systems in Canada and Australia

With the emergence of human rights, and especially the human rights of people with disabilities, guardianship systems have been progressively looked at critically: it did not serve people with intellectual disabilities well. Families and professionals were gradually becoming aware of the need to promote the independence of young people with disabilities (Carney and Tait, 1997). Audrey Cole recalled her first critical reading about guardianship from a conference booklet dated from 1959 describing *“that mechanisms that would keep the options open for people with disabilities as they gained confidence from new experiences in the broader and gradually more welcoming community”* are needed (Cole, 2015).

Australia and Canada are somewhat trailblazers in the development of decision-making procedures which allow for more autonomy and attempt to overcome the tension between protection and independence (Carney and Tait, 1997; CACL Task force on alternatives to guardianship, 1992; CACL, 1998; Cole, 2015).

The general characteristics of the early reforms of guardianship in the 1970s and 1980s in Australia and Canada comprise the adoption of safeguards to avoid abuse, regular reviews and a commitment to the least restrictive alternative, guardians being appointed only as a matter of last resort (Carney and Tait, 1997; Gordon, 2000). They moved to the notion of partial autonomy – instead of complete loss of capacity, they introduced limited decision-specific restrictions (Verma and Silberfeld, 1997).

In contrast, respect for autonomy and promotion of independence were becoming central to the alternative decision-making models adopted in the third wave of reforms during the 1990s (Gordon, 2000). At the same time new models were backed by a system of checks and balances to avoid abuse. A central element of guardianship systems in Australia was for example the Public Advocate, whose central role was to act as a watchdog over the Guardianship and Administration Board[9] and ensure that protection did not supersede autonomy. This function included: *"1. undertaking truly independent investigations 2. appearing before the board to argue a matter 3. challenging the board over 'inappropriate' decisions 4. encouraging applicants to appeal (if it is believed a mistake has been made) 5. undertaking research to check out the outcomes of the board's procedures"* (Carney and Tait, 1997).

At the beginning of the 1990s, discussions about adult guardianship legislation and proposals for reforms were put on the political agenda in several provinces in Canada (Nova Scotia, British Colombia, Ontario). A Coalition on Alternatives to Guardianship was created in the autumn of 1992 by Community Living Ontario, People First of Ontario, People First of Canada and the Canadian Association for Community Living ('the Coalition'). The Coalition's foundational statement of principles states that all individuals have the right to self-determination. The objective of the Coalition is not to implement another legal reform but to propose a "new paradigm" for decision-making, challenging the view that people are incapable of making choices about their lives. The new paradigm *"recognises that self-determination and autonomy can be expressed in the context of relationships with others, and that interdependence, not only independence, is a valid and meaningful way of making choices and decisions" (*CACL, 1992). They claim the right for all individuals to make decisions with the help of people they have chosen – help to make decisions and to communicate these decisions and refuse any assessment of competences or tests to appoint a substitute decision-maker (Coalition on Alternatives to Guardianship, 1992). This notion of *interdependence* challenges the construct of a legal person and how decisions are presumably made. This notion of interdependence gradually became central and brought a new model based on the importance of informal supports and relationships, reflecting the reality of decision-making for many

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[9] Adopted in Victoria, Western Australia and South Australia

people: this model was called assisted or supported decision-making (Gordon, 2000).

This new right to support in making decisions was accompanied by a system of checks and balances, incorporating review mechanisms, abuse legislation and accountability safeguards (Coalition on Alternatives to Guardianship, Calgary, 1993). The policy documents and the law reforms proposals reflected the idea developed by Wolfensberger about Normalisation, such as, for example, the concept of the “dignity of risk” used in the association’s document as a counter element of the best interests protection (Gordon, 2000).

The core reform elements of the new paradigm presented by the Coalition can be summarised by the need to build different kinds of “ramps” to ensure access to equality in decision-making for people whose legal capacity is challenged because of their disabilities: legislative and personal support ramps (Cole, 2015).

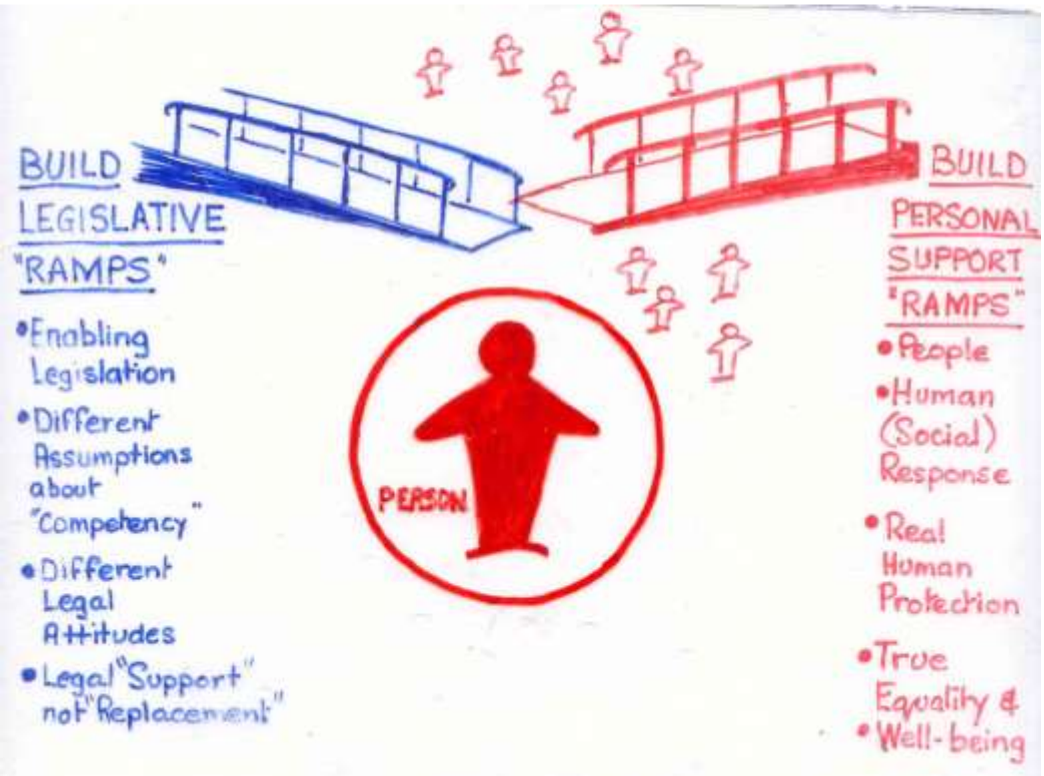

Figure 1: Preserving the Right to Self-determination: Supported Decision-making (An Alternative to Guardianship), presented by the Coalition on Alternatives to Guardianship at a pre-conference workshop for self-advocates on 20 October 1993, Calgary, Alberta, Canada. The drawing shows two ramps to build: legislative ramps and personal support ramps.

This model of assisted or supported decision-making was viewed as a viable alternative to substituted decision-making and became the option supported by organisations of people with intellectual disabilities (CACL, 1992; Gordon, 2000).

In 1996, Manitoba included the recognition of supported decision-making in the Vulnerable Persons Living with a Mental Disability Act (applying only to people with intellectual disabilities). It poses four key principles which will become common to other reforms: 1. the importance of making one's own decisions, 2. the importance of a support network to assist and enhance the person's self-determination, 3. the doctrine of the least restrictive and less intrusive form of intervention; and 4. the principle that substituted decision-making is used only as a last resort (Gordon, 2000). In parallel, the British Colombia's Representation Agreement was adopted in 1996 but entered into force in 2000 only, because of a failure to implement legislation, at least in part, due to a clash between disability rights theory and seniors' rights theory (Bach and Kerzner, 2010; Gordon, 2000). Early reformed provinces were then followed by others in the next decade, thus providing several examples of supported decision-making, sometimes limited in scope (like in Alberta only for personal matters) and always along with other measures of co-decision or substituted decision-making (guardianship) as last resort.

These early reform efforts strongly influenced and still influence the debates in other countries and paved the way for future reforms towards supported decision-making as enshrined in Article 12.

Several problems and criticisms were also identified with the emergence of supported decision-making. First of all, the influence by the intellectual disability movement created competing voices versus the older people's movement, which traditionally had been driving the agenda on guardianship (Gordon, 2000; Nidus, 2010). The formalisation of supported decision-making also brought several concerns: the risks of destroying informal relationships (caring and trusting relationships), potential conflicts arising from supporters' different views, the question of who will provide assistance to people without a network, and how to perform the task of informing/providing information without interference while not failing to act when needed, and finally the risk of undue influence of supporters and abuse (Gordon, 2000). To address and prevent undue influence, abuse and neglect, three types of safeguards and accountability measures were foreseen: safeguards which are built into the process itself through standards and procedures (like duties and guidelines for supporters), review processes, including monitoring, detection and resolution of conflicts between the supporters and the supported person and mechanisms to report abuse and neglect (CACL, 1992).

The Canadian reforms principles were then presented five years later in 1998 at the XII World Congress of Inclusion International in The Hague in Europe (CACL, 1998), where reforms had been going at a slower pace.

1.2 Guardianship in Europe: diverse models and slow reforms

In Europe, reform efforts to modernise guardianship laws have been more diverse but often less progressive than the early reform efforts such as in Canada. Before the reforms, models of incapacitation were very similar to minors' protection (European Parliament, 2008). In 2013, several European countries still had very outdated guardianship laws – the oldest one being the Irish Lunacy Regulation Act from 1871 (FRA, 2013). In Western Europe, most reforms brought modernised and more flexible guardianship laws, giving procedural guarantees, especially to the person concerned and respecting the dignity of each individual, but, in essence, they remain anchored in the substituted decision-making model (Dinerstein, 2016; Booth Glen, 2012). In contrast, they would remain unchanged for many more years in Central and Eastern Europe.

The national legal systems aimed to better reflect the Recommendations No. R 99 (4) of the Council of Europe on Principles concerning the legal protection of incapable adults[10], which predates the CRPD. The recommendations are nonetheless still used as reference in case-law of the European Court of Human Rights (hereinafter ECHR) and their guidance may be useful material for the implementation of Article 12 at national level. The Recommendations contain several principles, among which the important ones can be summarized as follow: protection measures should be necessary, proportional to the person's capacity (Principle 5), tailored to the individual circumstances and needs (Principle 6). A person's interests and welfare, past and present wishes and feelings should be ascertained and given due respect (Principle 9). There should be no automatic loss of other rights, no complete removal of legal capacity and a maximum preservation of capacity (Principle 3). Available measures should be flexible (Principle 2). While not referred to as supported decision-making, the Recommendations also introduced this notion by recognising that assistance in decision-making may be provided by family members or by others (FRA, 2015). A comprehensive set of safeguards is included: limited duration of measures of protection with periodic review and the right to appeal (Principle 14) but also proper assessment of capacity and participation of the person both in the assessment process (Principle 12) and the right to be heard in the proceedings (Principle 13). The recommendations also offer guidance about the way a guardian should be chosen: the wishes of the adult should be respected. The guardian should inform the person about decisions to allow the person to express his/her view (Principle 9).

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[10] https://www.coe.int/t/dg3/healthbioethic/texts_and_documents/Rec(99)4E.pdf (last accessed 27/7/2021

Comparative studies of the field of adults' protection show that most states distinguished co-existing different forms of protection based on an assessment of the degree of impact on the person's legal capacity (European Parliament, 2008; Fallon-Kund and Bickenback, 2017). The reforms of guardianship laws also included similar patterns, reflecting the introduction of the Council of Europe's recommendations: the principles of necessity, subsidiarity (that is to say that in principle decisions are made by the person independently and only when it is not possible some measures should be adopted) and proportionality (the less restrictive measure should always be preferred); as well as the re-examination of protection measures on a regular basis, the right to appeal and taking into account the will of the person (Fallon-Kund and Bickenback, 2017).

The reformed legal frameworks in Europe can be divided into four categories: models based on self-determination, models based on a functional approach, modernised guardianship laws and outdated guardianship laws. Each category is briefly presented in the following sections with some examples.

1.2.1 Models based on self-determination

First, a number of countries have adopted models based on self-determination, presuming that the person is able to make decisions for him/herself. They are characterised by a less formalistic regime and more flexible models, where a decision-maker is assisted by a representative in areas where needed. The term incapacity is obsolete in the case of Sweden and Germany, and a person with limited capacity can no longer be labelled as incapable (European Parliament, 2008). Automatic loss of capacity is not possible anymore. Sweden with three different instruments and Germany with one instrument illustrate how the principle of self-determination has become central and that of protection measures the exception. At the same time, both systems maintain forms of substituted decision-making and exceptions to the principle of self-determination, thus allowing forms of substituted and supported decision-making to coexist.

Sweden abolished total guardianship in 1989 and replaced it with two models: the mentor (*god man*) or the trustee (*förvaltare*). Both models can provide assistance in exercising rights, administrating property and taking care of oneself, but protection measures should apply only if informal assistance by a friend or a relative is not feasible (European Parliament, 2008). However only in the mentor model does the person retain full legal capacity. It offers flexible assistance, based on dialogue and cooperation and this assistance is always voluntary, never imposed (FRA, 2013). By contrast, the trustee model implies that the trustee can take decisions on behalf of the person with a disability, when the person cannot take care of him/herself or his/her property (European

Parliament, 2008; FRA, 2013). The limitation of legal capacity to act is clearly defined in the mandate of the trustee, and his/her mandate should also be strictly limited to the necessary tasks that the person is not able to perform. However, every person under trusteeship can always act, can always enter an employment contract and enjoy the fruits of the employment, and the right to vote and to marry cannot be limited. The 2006 statistics show about 7,192 persons under trusteeship (*förvaltare)* and 62,795 having a mentor (*god man).*

In 1995, in the framework of its psychiatric reform, Sweden also adopted the Personal Ombudsmen (*PO personligt ombud*) model. The PO has been praised in many policy and academic texts as being one of the rare models in compliance with Article 12 (ENNHRI, 2020; Booth Glen, 2012 and 2018; Gooding, 2013 and 2017; Minkowitz, 2007; Morrissey, 2012; United Nations, 2007). The PO model started as a pilot programme to help patients to access their rights and it has proven to be successful also for people with severe psychosocial disabilities. The PO model has three main characteristics: 1) the PO is a skilled independent professional, who works only on his/her client's request; 2) the PO works only with the person (not with psychiatrists, services, authorities or families); 3) the PO first concentrates on building a trusting relationship, which may take a long time and require creativity and unconventional ways to engage the person. A trusting relationship is the condition for working together. This means that things may stay chaotic for a while. To sum up, the PO is a flexible, non- bureaucratic model which reacts to the client's wishes[11].

In 1992, Germany adopted the *Betreuung* model (often translated as "custodianship"), based on the right to self-determination and legal representation and abolished the previous model of *Vormundschaft*, based on total incapacitation. The 1992 law has been amended several times since then to better comply with international standards. Free will, autonomy and self-determination to the greatest extent possible are at the centre of the law, which focuses primarily on the assistance needs of the person. There is no loss of rights and people with disabilities retain the right to marry, to make a will and to vote. In contrast to the Swedish model, only a "custodian" (*Betreuer*) can be appointed. The law also includes a measure to anticipate future decisions in case of loss of capacity (lasting power of attorney).

While in principle there is no restriction of legal capacity, the scope of the custodian's work depends on the level of needs of the adult and should be

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[11] For a description of the PO model by Maths Jesperson on the website of the association of PO in Scania county http://po-skane.org/in-foreign-languages/ last accessed 30/7/2021

limited to what is absolutely necessary. The custodian should help and support the person in taking care of his/her own affairs (health, housing, financial means, representation in public authority matters). The principle of necessity and subsidiarity are central in determining the needs of each adult. In practice, both the person and the custodian can legally act. When the custodian acts as a representative he/she must find out and respect the preferences of the person (paragraph 1901). However, the German National Monitoring Body commenting about the compliance between Article 12 and the German legislation notes that although legal guardians must abide by the wishes of the persons they represent in practice this existing supported decision-making component is neglected - they do not abide by the person's wishes (German Institute for Human Rights, 2015). In addition, paragraph 1903 of the law is seen as problematic, because it permits restrictions of legal capacity, in case of substantial harm to the person or his/her property. Under this paragraph, adults need the authorisation of their custodian for every legal act falling within the scope of the custodian’s attributed powers (except personal matters, like marriage and partnership or will). This paragraph, even though used in perhaps only 1% of cases, has long been regarded as problematic by disability organisations, and in contradiction with Article 12[12].

The German and the Swedish models show that there is long-term experience of models based on self-determination where the principles of necessity, subsidiarity and proportionality are in place but those models have not yet been applied universally for all, as there are still cases in which decisions are being made for people by others. While the shift from protection to autonomy is emphasised, the systems also maintain a kind of grey area between substituted and supported decision-making (Salzman, 2009), because where the person has full legal capacity, there is no guarantee that the will and wishes of the person have primacy.

Another model has been considered as progressive in that it aims to disentangle incapacity and disability: the Mental Capacity Act of England and Wales.

1.2.2 Models based on the functional approach

The Mental Capacity Act 2005 (hereinafter MCA) presents another interesting model. First of all, the MCA recognises the right to make decisions for oneself. The MCA includes the principle of the presumption of capacity, which means that a person is considered to have capacity unless it is established that this person lacks capacity. The MCA presumption of capacity is decision-specific and time-specific: a person might be found to lack capacity for one particular

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[12] Notes taken by the author and presentation by Karin Stumpf, Leben mit Behinderung, from 26 to 28 September 2011 in Hamburg (Study Visit organised by Inclusion Europe).

decision but it does mean that this person lacks capacity to take other decisions (Parker, 2021). The MCA also says that people must be given all practicable support to make their own decisions before they are considered to lack the capacity to make that decision (section 1.3 MCA[13]). A person is not to be regarded as unable to understand the information relevant to a decision if he/she is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means). The accessibility of information and of formats to communicate decisions is an essential element of the MCA.

Section 2 of the Mental Capacity Act states that "*a person lacks capacity in relation to a matter if* ***at the material time*** *he is unable to make a decision for himself* ***in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain***". Accordingly the assessment capacity can be seen as a two-stage test: the "functional element" and the "diagnostic element" (Parker, 2021). First of all, the "functional test" considers whether the person is unable to do any one of the following four things, as set out in section 3 (1) MCA:

1. To understand the information relevant to that decision (which includes the reasonable foreseeable consequences of the decision) (in accessible formats)
2. To retain the information
3. To use or weigh that information as part of the process of making the decision, or
4. To communicate the decision (also using alternative means)

Secondly, the assessment includes the 'diagnostic element' in that if the person is unable to make the decision (the 'functional element') they will only lack capacity if that inability to decision is 'because of an impairment of, or a disturbance in the functioning of the mind or brain' (the diagnostic element'). The test comprises three questions: first, if the person has the ability to make the decision, including with appropriate support. If, with that support, the person is able to make the decision, there is then no need to go further: they have capacity to make it (Ruck Keen et al., 2022). Only if the person is unable to make the decision, does the question whether they have an impairment of the mind or brain become relevant. If they do, those assessing the person's capacity then need to ask whether that impairment is the reason for the person's inability to make the decision in question. It cannot be a general assumption;

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[13] A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success (section 1.3 MCA)

the MCA requires the inability to be "because of" of the impairment (Ruck Keen et al., 2022).

Decisions made on behalf of someone who lacks capacity can be made in the person's "best interests". The MCA's best interest standard differs from the traditional best interest approach which gives little attention to the person's view (Parker, 2021). Although there is no definition of "best interests" several things must be done in a best interest decision. It is important to note that this is mandatory not discretionary (Lush, 2015). These standards include maximising the participation of individuals in the decision-making; taking into account past and present wishes, feelings, beliefs, values and any other information that is relevant; considering if the person may have capacity in this matter in the future and developing the skills needed; and finally, consulting with family members, carers and other people who have an interest in the person.

Critical views of the use of MCA show that in practice some principles are distorted from their original aim. The Everyday Decisions project[14] for example highlights the gap between everyday choices and more complex decisions or legal future planning tools, such as wills, advance directives and power of attorney (Harding and Tascioglu, 2017). The report found that nuanced, person-focused and multi-sensory techniques are used to support choices about everyday matters and choices are respected. But decisions about housing, finances and health care are much more challenging, often out of the control of the person, based on the "best interests" framework rather than supporting people (Harding and Tascioglu, 2017).

Research also shows that capacity assessments are typically triggered when somebody makes a problematic choice (Emmet et al., 2012; Williams et al., 2012, cited by Series, 2013a). Although the MCA explicitly states that a person is not to be treated as unable to make a decision merely because he/she makes an unwise decision (Section 1 (4) MCA), research shows that unwise decisions were very difficult to disentangle from an assessment that someone lacked capacity. And this was especially visible when the assessment was made on the basis of lack of understanding of one's own needs for protection and care (Williams et al., 2012, cited by Series, 2013a). Therefore, as Lucy Series argues, people who do not have the capacity to convince and articulate their case are more impacted by functional tests (Series, 2013a).

Research conducted by The Essex Autonomy Project (EAP) concluded that the MCA is not fully compliant with the CRPD and made recommendations to

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[14] The Everyday Decisions project website and blog: www.legalcapacity.org.uk (last accessed 4/9/2021)

address this. For example, EAP noted that the MCA violates the non-discrimination provisions of the CRPD because the finding of incapacity is restricted to those who have *an impairment of, or a disturbance in the functioning of, the mind or brain* and therefore recommended that section 2(1) should be amended so that disability and incapacity are "de-linked" (Martin et al, 2016). EAP also recommended adopting a rebuttable presumption approach. It means that "*a best interests decision-maker must start from the presumption that, when a decision must be made on behalf of a person lacking in mental capacity, and the wishes of that person can reasonably be ascertained, the best interests decision-maker shall make the decision that accords with those wishes"* (Martin et al, 2016). Where appropriate, an independent advocate or a trusted person for example could be involved to help identifying and articulating those wishes (Martin et al, 2016).

The key principles of the MCA put an emphasis on accessibility and support in the first place, thus giving priority to the right to take decisions. In contrast, Civil Codes countries have developed a panel of measures, within guardianship systems, aiming to offer tailored answers to those whose capacity is challenged.

1.2.3 Late reforms of guardianship law

The third group of legal systems includes modernised guardianship laws, which have abolished plenary guardianship and have included new measures of protection used as an alternative to guardianship and better procedural safeguards, to take into account the rights and will of the person. Reforms in France and Italy for example illustrate this path. It is important to note that these reforms happened in parallel with the negotiations of the CRPD, but seems to be disconnected from the debates and the challenges around legal capacity and the future article 12.

The 2007[15] French law on guardianship retains the original three protection measures (1. guardianship - *tutelle* 2. curatorship - *curatelle*, and 3. judicial safeguard - *sauvegarde de justice*) but they were remodelled and two additional measures were introduced (social measure and lasting power of attorney). The reform includes a more active participation of the person in the proceedings, a better account of his/her needs and wishes, and a right to appeal[16], following the Recommendations 99(4) of the Council of Europe.

Three measures as alternatives to guardianship are now available: first of all, the revised judicial safeguard (*sauvegarde de justice*); it is a measure, with no

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[15] The law was adopted in March 2007 and entered into force on 1 January 2009 – while the CRPD entered into force in France in March 2010. This timing seems like a missed opportunity to work on a more profound reform of the system of guardianship.

[16] Articles 1239-1240 of the French Code of Civil Procedure

restriction of legal capacity to provide temporary protection or representation for specific legal acts (e.g.: selling a house). Secondly, a social measure for people experiencing difficulties managing their social benefits[17] and at risk in terms of health or safety (including at risk of losing their housing) was created – this measure should help them to deal with money management and to recover the capacity to manage their budget independently. Finally, the third measure is a lasting power of attorney (*mandat de protection future)*: the person can name one or more people to look after his/her well-being and manage his/her affairs, in the event that the person may not be able to do so.

Several French organisations have criticised the application of the law in practice and especially the lack of relevant data available to make a detailed analysis of the impact of the law (CNAPE, FNAT, UNAPEI[18]). The general trends show that the number of measures of protection is increasing, but the part of the alternative measures (with no limitation of legal capacity) is still very small compared to traditional protection measures – thus indicating a failure compared to the primary objective of the reform, which planned major use of alternatives (CNAPE et al., 2012). The absence of demographic data about who the protected persons are, does not allow monitoring the use of measures for people with disabilities and elderly people (Peterka et al., 2012). There is also a lack of accommodation and alternative formats of the proceedings to better take into account wishes and preferences of the person, as foreseen with the reform (AJuPID, 2015). Finally, the complexity and lack of flexibility to better adapt the alternative measures is also criticised: for example, there is a consensus that the social measure should be open to a larger group of people than only those who receive social benefits, so that people who need support with money management for any reason could benefit from this measure (AJuPID, 2015; CNAPE et al., 2012). This would help to create a really useful alternative to guardianship for a larger group of citizens.

The Italian reform of 2004 (law number 6/04[19]) introduced the figure of the *ammistratore di sostegno* (support administrator), allowed to represent the person with a disability in certain specific acts. The aim of the administrator is to support the person's decision-making capacity rather than make decisions on the person's behalf, with the objective to preserve the dignity of the person

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[17] This measure of social support includes, in fact, two measures (*Mesure d'accompagnement social personnalisé* and *Mesure d'accompagnement judiciaire*) - the second one being proposed in case of failure of the first one.

[18] See their joint White Book published in 2012, including 25 propositions to improve the adult's protection legal framework: https://www.unaf.fr/IMG/pdf/livre_blanc_bd2.pdf (last accessed 4/8/2021)

[19] See the text of the law available at https://www.parlamento.it/parlam/leggi/04006l.htm (last accessed 19/12/2022)

while keeping his/her legal capacity to act to the maximum extent. The person can act in all the areas which are not under the responsibility of representative and that always includes daily acts, which cannot be limited. The administrator offers support both in the field of personal decisions and the field of assets and finances. Practice shows that in the past years more importance has been given to personal decisions rather than the traditional protection of assets (Vigani, 2010). In contrast with France, the incapacity procedure became progressively obsolete with this new measure of the support administrator. Despite the adoption of the Law 6/2004 introducing the Support Administrator, the national legislation still allows the withdrawal of legal capacity on the basis of inability of "sound mind".

The French and the Italian models have not followed the same path as other European countries, but they have introduced some alternative measures co-existing with traditional guardianship measures. While the primary focus of these measure was money and assets management, the Italian example shows that the model has expanded towards personal decisions.

Reforms of outdated incapacitation models in Central and Eastern Europe tentatively began in the last decade.

1.2.4 Unreformed guardianship models in Central and Eastern Europe

In the early 2000s, most Central and European Countries still had capacity laws from the 1950s or the 1960s, drafted under the former Communist regime. The prevalence of plenary guardianship is also higher in those countries. The Mental Disability Advocacy Centre compared the number of people under plenary guardianship against the number of people under partial guardianship finding that the ratio was: 76% versus 24%, in Bulgaria, Croatia, the Czech Republic, Hungary, Moldova, Slovakia and Poland (MDAC, 2013). Constitutional Courts in Poland[20] and in the Czech Republic[21] have, however, acknowledged the outdated systems applies in their countries and the need to take tailored measures and respect the human rights of people with support needs in the exercise of their legal capacity.. Latvia's Constitutional Court ruled[22] that Articles 358 and 364 of the Civil Code did not conform with the Constitution on

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[20] Polish Constitutional Tribunal, Judgement K 28/05 on file with author, also cited in FRA 2013.

[21] Czech Constitutional Court, (Ústavní soud) 18/8/2009, sp. zn. I. ÚS 557/09, available at: http://nalus.usoud.cz/Search/GetText.aspx?sz=1-557-09 (last accessed 31/7/2021). It is only in 2014 that a new Civil Code will enter into force in the Czech Republic with a modernised guardianship system and alternatives to the legal capacity limitations (see chapter 6 for more details as a pilot project realised in the Czech Republic is part of this study).

[22] This judgement was ruled in December 2010, just after the country's ratification of the CRPD earlier in 2010. Consequently, on 29 November 2012, the Latvian parliament adopted extensive amendments abolishing plenary guardianship and introducing revisions of the Civil Code.

the basis that they unreasonably restrict a person's right to a private life. This is because there were no provisions for partial guardianship - the only option to deprive a person of their legal capacity was to impose a full deprivation of legal capacity (FRA, 2013). Following this decision plenary guardianship was abolished.

The above examples illustrate that Article 12 CRPD was drafted at a time when in this context where progressive models for decision-making (which combine elements of supported and substituted decision-making) coexisted with outdated systems of guardianships.

1.3 The genesis of Article 12

As mentioned in the introduction, the tensions between protection and autonomy have been at the centre of the *travaux préparatoires* around Article 12. The International Disability Caucus, representing the majority of civil society actors, disabled people's organisations and other NGOs, negotiated with a strong and united voice towards governments, but also tolerated ambiguity in some areas to guarantee that all members would support the position reached (Series and Nilsson, 2018). Most of the debate concentrated on the question of whether people with disabilities have legal capacity in the sense of having the capacity to exercise this right (that is the capacity to act)[23], as the meaning of legal capacity in different legal systems may have been interpreted differently. However, the International Disability Caucus maintained "capacity to act", as it is essential to self-determination (Dhanda, 2007; Minkowitz, 2007; Series and Nilsson, 2018). Many countries justified their position by referring to so-called extreme cases or exceptional situations (such as a person in a coma) for which they would require full substituted decision-making (Schultze, 2010; Martin et al., 2016). As Marianne Schultze described, one of the major challenges was "*to make clear that while support can vary from 0% to 100%, the higher end of the spectrum is rare when an adequate support system is actually put in place*" (Schultze, 2010). To illustrate this debate, two draft proposals of Article 12 can be read:

The proposal made by Canada for the third and fourth session of the Ad-hoc Committee still retains the possibility of a person being found not to have legal capacity (Schultze, 2010; Martin et al., 2016):

> […] 2. States Parties shall ensure that where persons with disabilities need support to exercise their legal capacity, including assistance to understand information and to express their decisions, choices and wishes, the assistance is proportional to the degree of support required and tailored to the person's individual circumstances.

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[23] See the ad-hoc Committee sessions available at https://www.un.org/esa/socdev/enable/rights/adhoccom.htm (last accessed 12/8/2021).

> 3. Only a competent, independent and impartial authority, under a standard and procedure established by law, including provision for review, can find a person unable to exercise their legal capacity with support. […]

In this version, the State Parties should ensure access to *assistance to understand information* and also to *express decisions, choices and wishes;* at the same time safeguards are included directly in the provisions for assistance: *proportional* and *tailored*. The third paragraph includes the situation of persons unable to exercise their legal capacity with support and maintains representation on behalf of the person. This drafting was removed later during the negotiations and no procedure for restricting legal capacity is further described. A later draft makes no provision for substituted decision-making, (reflecting the position of the International Disability Caucus) (Schultze, 2010). However, state representatives continued to insist on some forms of substituted decision-making (6 countries[24] are quoted in Martin et al., 2016).

At the 7th session of the Ad-hoc Committee, in October 2005, the draft of Article 12 Equal recognition as a person before the law, reads as follows:

[…] 2. States Parties shall recognise that persons with disabilities have [legal capacity] on an equal basis with others in all fields and shall ensure, to the extent possible, that where support is required to exercise [that capacity] [the capacity to act]:

(a) The assistance provided is proportional to the degree of support required and tailored to the person's circumstances, that such support does not undermine the legal rights of the person, respects the will and preferences of the person and is free from conflict of interest and undue influence. […] such support shall be subject to regular and independent review;

(b) Where States Parties provide for a procedure, which shall be established by law, for the appointment of personal representation as a matter of last resort, such a law shall provide appropriate safeguards, including regular review of the appointment of and decisions made by the personal representative by a competent, impartial and independent tribunal. […][25].

This draft shows the debates around the meaning of legal capacity, including capacity to act. H.E. Ambassador Mackay, the Chairman of the Ad-Hoc Committee, accompanied this draft with the following comment:

> *I hope it will be possible to resolve this matter by distinguishing between (a) the possession of legal capacity by all persons, and (b) the exercise of that capacity, which may require the provision of assistance in some circumstances. I note that the Convention on the Elimination of All Forms of Discrimination against Women in Article 15 (2), for example, uses the term "legal capacity" and in the same paragraph refers to "exercising" that capacity; it does not refer to "capacity to act". I therefore suggest that we stick to*

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[24] Japan, Kenya, New Zealand, Thailand, Norway, Serbia and Montenegro.

[25] See the Working text of the CRPD as discussed at the 7th session of the ad-hoc Committee, available at https://www.un.org/esa/socdev/enable/rights/ahc7report-e.htm last accessed 12/8/2021

> *the term "legal capacity" as used in that Convention, which would mean deleting the language in the last set of square brackets in the chapeau to paragraph 2.*[26]

Secondly, this draft still includes the term "personal representative". The International Disability Caucus thought that leaving these words would open the door to use of guardianship. To reach a compromise solution, it was decided, as proposed by International Disability Caucus, that the text of Article 12 would neither prohibit nor endorse substituted decision-making (Dhanda, 2007). However the intention not to exclude people with high support needs was strongly defended during the negotiations (the notion of 100% support was often used during the negotiations). Several authors have argued that interpreting in narrow way, thus permitting substituted decision-making, would empty Article 12 of its content and its paradigm shift (Schultze, 2010; Dhanda, 2007; Minkowitz, 2007). However, others argue that members of the ad-hoc Committee insisted on the necessity of substituted decision-making and that they would never have accepted a ban on it (Martin et al., 2016). So the best compromise was to adopt a language that neither prohibits nor endorses it.

The final version of Article 12 reads as follows with five paragraphs:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

This paragraph is consistent with other international treaties (Art. 6 UDHR; Art. 5 ICERD; ICCPR Art. 16 or art. 15 CEDAW).

2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Article 12 in its second paragraph thus calls for an end of systematic deprivation of legal capacity because of their disability (CRPD, 2014). Legal capacity covers the capacity to act and the right to exercise (enjoy) this capacity in all fields. It echoes the language of CEDAW on legal autonomy[27].

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Paragraph three completes the previous one. Legal capacity cannot be removed but support should be provided. Support arrangements should be available of varying types and intensity, including formal and informal to include those requiring more intensive support (Human Rights Council, 2013; CRPD, 2014). The use of the word 'support' (earlier drafts used 'assistance') was specifically

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[26] See paragraph 53 of the Letter dated 7 October 2005 from the Chairman to all members of the Committee available at https://www.un.org/esa/socdev/enable/rights/ahcchairletter7oct.htm last accessed 12/8/2021

[27] See General Comment 21 on equality in marriage and family relations: "When a woman cannot enter into a contract at all, or have access to financial credit, or can do so only with her husband's or a male relative's concurrence or guarantee, she is denied legal autonomy. Any such restriction prevents her from holding property as the sole owner and precludes her from the legal management of her own business or from entering into any other form of contract. Such restrictions seriously limit the woman's ability to provide for herself and her dependants".

chosen to ensure that there would be no loophole into which any form of substituted decision-making would fit (Schultze, 2010).

> 4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

The fourth paragraph illustrates the tension between substituted decision-making and supported decision-making. The first part “respect for rights, will and preferences, are free of conflict of interest and undue influence of the person” refers to a language where the person makes choices, the person is the decision-maker. The second part of this paragraph and especially the second sentence contain elements which by referring to the proportionality and tailored measures to the person’s circumstances evoke guardianship-type measures and a paternalistic approach to people with disabilities. The final text of Article 12 (4) is an attempt to combine some of the safeguards that had been proposed for substituted decision-making to supported decision-making (Dhanda, 2007). This ambiguous text thus received the support of the majority of the states.

> 5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

This last paragraph specially looking at finances and property, which have been particular areas of abuses and violations of rights of people with disabilities, seems unnecessary with the provision on universal legal capacity in all areas of life (paragraph 2) and provision of support to exercise legal capacity (paragraph3) and it seems to endorse substituted decision-making (not being arbitrarily deprived of their property). Financial independence is of vital importance for people with disabilities, which may justify a specific paragraph in this article.

Last but not least, before the end of the Ad-hoc Committee, a footnote appeared in the consensus text stating that “in Arabic, Chinese and Russian” the term “legal capacity” refers to “legal capacity for rights” rather than “legal capacity to act”. This was a critical moment to the meaning of Article 12 and the whole CRPD. This footnote had not been discussed earlier (Dhanda, 2007; Schultze, 2010) and both DPOs and the “legal and diplomatic forces” worked against it. Eventually, the footnote was removed.

The CRPD entered into force in 2008, after a swift ratification process, and a number of reforms have taken place with views to ratify or to align national legislation to the CRPD. Reform efforts to comply with Article 12 have proven to be a challenge at national level (Fallon-Kund and Bickenback, 2017), as the following examples illustrate.

1.4 Post CRPD reforms

According to the European Union Fundamental Rights Agency, legal capacity remains one the areas with the largest number of reforms at the national level linked to CRPD ratification 10 countries out of the 27 EU member States reported reforms (FRA, 2015). However, as far as comparison is possible, no country has totally abolished substituted decision-making.

Austria and Ireland adopted new models attempting to reach universal legal capacity, as part of the effort to make their legislation compliant with the CRPD.

1.4.1 Austria

Following strong criticisms by the CRPD Committee in its Concluding Observation in 2013 about the existing legislative framework, the Austrian government decided to revise the existing law in a 2-year process. The legislation called the New Adults Protection Law entered into force on 1 July 2018[28]. The highlights of the Austrian case are its participatory reform process and the so-called “clearing” mechanism. The reform process included participation of all groups (guardians’ associations, people with disabilities, including people under guardianship, lawyers, senior-citizens, representative of care facilities, and others) who worked in small expert groups on the reform. The results were discussed in broader groups where special attention has been paid to the accessibility of the debates (e.g.: using plain language, sketches and accessibility cards). In parallel, a pilot project was prepared in collaboration with the guardians’ associations to check the available alternatives to substituted decision-making. The process was also monitored and evaluated by a group of researchers at the Austrian Institute for the Sociology of Law and Criminology. According to the Ministry of Justice, alternatives were found for 90% of the group of people under guardianship targeted. The alternatives should be found by a “clearing” process carried out by publicly funded adult protection associations (formerly “Guardians’ Associations”).

The clearing process does not focus on a medical assessment but aims to give a full picture of the individual circumstances. The clearing process is now a

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[28] https://www.ris.bka.gv.at/Dokumente/BgblAuth/BGBLA_2017_I_59/BGBLA_2017_I_59.html (last accessed 7/8/2021)

mandatory part of the process and should be provided in Court proceedings for the appointment of representatives. The “clearing” process is done by an adult protection association which establishes the situation of the individual concerned: specific issues that need to be addressed; risks that are identified; support needed to have the capacity to act; the social environment or institutions, authorities or associations which offer opportunities for support[29]. The aim, where possible, is to avoid the need for a court-appointed representative by finding adequate support.

The Act is guided by the principles of autonomy, self-determination and decision-making guidance (ENNHRI, 2020). Four types of schemes for representing adults requiring assistance have been adopted, each offering different powers to ensure greater self-determination by the individual concerned. None of these mechanisms results in the automatic loss of legal capacity. The four schemes are 1. Enduring power of attorney; 2. Elective representation available to people whose decision-making capacity may be challenged; 3. Statutory representation and 4. Court-appointed representation. All schemes, of whatever type, must simply be recorded in a central register. For the three first pillars, the Court is involved only in sensitive or complex decisions. Only the fourth pillar implies a judge’s decision. Also only on the fourth pillar, if necessary, the judge can limit the capacity to act on certain legal acts (such as contract) but never on daily acts[30].

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[29] See information on the website of Vetretungsnetz, an adult protection association: https://vertretungsnetz.at/ (last accessed 7/8/2021)

[30] See the information on the website of the Austrian Ministry of Justice: https://www.justiz.gv.at/home/service/erwachsenenschutz~27.de.html
including an easy-to-read brochure:
https://vertretungsnetz.at/fileadmin/user_upload/4_Erwachsenenvertretung/ErwSch_Broschuere_LL_2017.pdf (last accessed 7/8/2021)

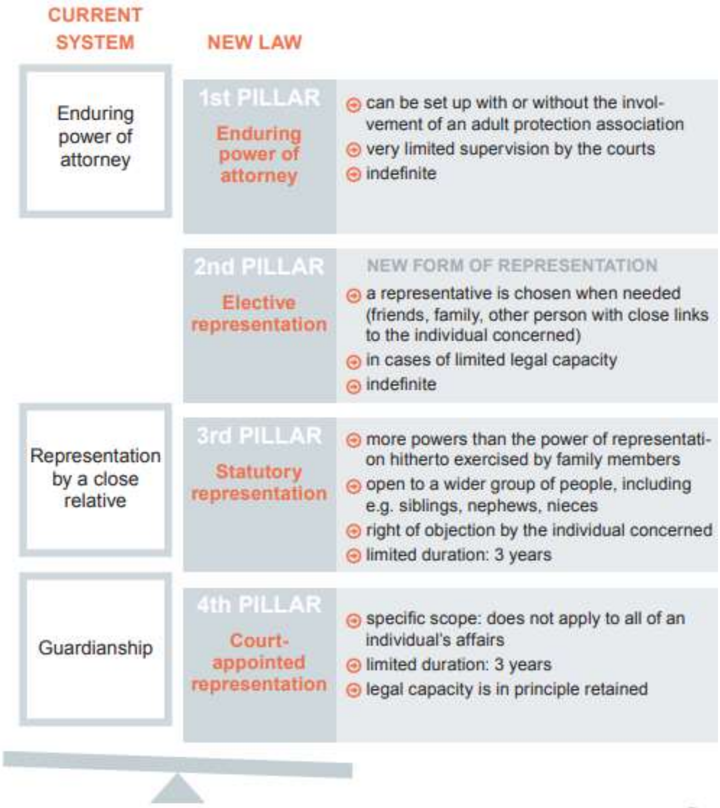

Figure 2: The figure describes the new protection measures of the Austrian lawn in comparison with the previous guardianship system. Graph published in a brochure by the Austrian Federal Ministry of Constitutional Affairs, Reforms, Deregulation and Justice about the New Adult Protection Law[31].

1.4.2 Ireland – the Assisted Decision-Making (Capacity) Act 2015

The campaign for legal capacity reform in Ireland has been followed with attention, as ratification of the CRPD was dependant on this reform. The out-dated model of ward of court (Lunacy Regulation Act 1871) was seen as the major stumbling block in legislation (Doyle and Flynn, 2013). Fifteen organisations (including the Centre for Disability Law and Policy at NUIG, Amnesty International, Alzheimer Society of Ireland, Age Action, National Federation of Voluntary Bodies, Shine, Inclusion Ireland, and the National Institute for Intellectual Disability at Trinity College Dublin) developed a set of rights-based "Essential Principles" (Amnesty International & The Centre for Disability Law & Policy 2011) intended to provide some guidance regarding the requirements of Article 12 to prepare the parliamentary committee hearings on the reform. The principles included a set of recommendations, to ensure that the new legislation would not take away people's rights to make their own decisions. Some recommendations read as follows: reasonable accommodation

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[31] See page 7 - available at: https://www.justiz.gv.at/home/service/erwachsenenschutz/informationsbroschueren~41.de.html last accessed 12/8/2021

should be made to help the person understand the decision, different ways of providing information must be explored (Amnesty International & The Centre for Disability Law & Policy 2011, Principle 4(a)); the law should allow people to plan in advance (Principle 5); advance planning should be subject to safeguards which ensure that the decision to appoint a representative reflects the will and preferences of the person (Principle 5(b)); decisions made by someone else for a person is a last resort to be used where the will and preferences of the individual are unknown and when all supports have been considered (facilitated decision-making). This should only apply for specific decisions and for the length of time necessary for that purpose (Principle 8). Finally, the Essential Principles also included a call for an independent decision-making body with a variety of disciplines. The coalition also argued that a courts-based system is not suitable for a flexible, accessible and individualised response (Principle 10(b)).

The final bill as adopted in December 2015[32] contains a number of advances as it introduced decision-making support options in line with the CRPD but it fails to embrace the paradigm shift required by Article 12. Indeed, the retention of the functional approach as a gateway to what are termed, under the Bill, "interventions" is contrary to Article 12 (Series, 2013b). A functional test of mental capacity remains the threshold to decide whether a person is able to make a decision (see Part I – 2(3) of the Act). The coalition was successful in having removed references to "best interests".

The guiding principles of an intervention, however, put great emphasis on the will and preferences of the person, as the intervener shall:

> *(a) permit, encourage and facilitate, in so far as is practicable, the relevant person to participate, or to improve his or her ability to participate, as fully as possible, in the intervention,*
>
> *(b) give effect, in so far as is practicable, to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable*
>
> *(c) take into account—*
>
> *(i) the beliefs and values of the relevant person (…)*
>
> *(d) unless the intervener reasonably considers that it is not appropriate or practicable to do so, consider the views of—*
>
> *(i) any person named by the relevant person as a person to be consulted on the matter concerned or any similar matter (…)*
>
> *(f) consider all other circumstances of which he or she is aware and which it would be reasonable to regard as relevant*

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[32] For the full text see ASSISTED DECISION-MAKING (CAPACITY) ACT 2015 – number 64/2015 available at: http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html (last accessed 12/8/2021)

Part 2 principles that apply before and during intervention in respect of relevant persons § 8 Guiding principles of the Assisted Decision-Making (Capacity) Act 2015

The provision that the intervener will give effect to a person's will and preferences *"in so far as is practicable"* will of course need to be monitored as how it works out in practice (Series, 2013b).

Among the panel of the five new measures[33] adopted, two supportive measures: decision-making assistance (in this model, the person retains ultimate decision-making responsibility) and co-decision making (joint responsibility basis) will be out-of-court procedures. Decision-making assistance is based on an agreement between the person asking for support and one or more persons of their choice. It can relate to personal welfare or to property issues and conduct of proceedings before any court or tribunal (ENNHRI, 2020). A third option is a Decision-making representation order (a substituted decision-making model when a person is deemed to lack capacity): it means that a representative is appointed by the court to make certain decisions on behalf of the person, taking into account his/her wishes. The new legislation also includes two future planning measures: advance Healthcare Directive and Enduring Power of Attorney (for people who have capacity at the moment they write it down).

With the adoption of the act, a Decision Support Service is being set up[34]. But five years later the planned opening of the Decision Support Service in 2018 has not happened because of funding shortfalls and it looks likely it may not until at least 2022[35].

Both the Austrian and Irish reforms have in common a large-scale participation of civil society groups, including people with disabilities and their representatives. But despite their broad involvement in framing the new law, both reforms stick to a mix of measures of supported and substituted decision-making. Thus these post CRPD reforms are not in line with the current interpretation of Article 12 by the CRPD Committee.

1.5 Synthesis

The idea of supported decision-making is not new, and its development illustrates the very slow process of propagation and implementation of this

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[33] Briefing Note by the Centre for Disability Law and Policy, Galway, on Legal Capacity Law Reform in Ireland – the Assisted Decision-Making (Capacity) Act 2015

[34] See https://decisionsupportservice.ie/ - the service should start running mid-2022. (last accessed 7/8/2021)

[35] See: news in the Irish Times, 21/9/2020 at https://www.irishtimes.com/news/social-affairs/replacement-wards-of-court-system-to-be-delayed-without-budget-funding-1.4359868 (last accessed 31/7/2021)

idea. From an historical perspective, the principles of subsidiarity, necessity and flexibility to respond to the needs of an individual have been introduced and improved progressively in several jurisdictions. Overall, the emphasis has shifted from protection to autonomy and support, despite wordings in most laws about protective measures (Fallon-Kund and Bickenback, 2017). The examples presented in this chapter also show that several supported decision-making measures are in force in different jurisdictions but they co-exist together with more restrictive regimes of substituted decision-making. Even the most recent legal reforms do not seem to be in compliance with the CRPD according to DPOs' opinions and the CRPD committee interpretation of Article 12. The main reason for this is the co-existence of supported and substituted decision-making models, which according to the Committee is not sufficient to comply with Article 12 (CRPD, 2014). At the same time, there is no unanimous view about the meaning of Article 12 – the genesis of the article clearly shows this ambivalence which still prevails a decade later. The interpretation of Article 12 CRPD remains a matter of debate between policy-makers or academics and the CRPD Committee or disability activists (see for example the EAP project or the FRA opinions). Some authors are calling for a more balanced and more realistic interpretation of Article 12 (Freeman et al., 2015; Fallon-Kund and Bickenback, 2017). Eventually the terms "substituted decision-making" and "supported decision-making" need to be better defined and fed with substance. And it should not be assumed that they carry their intuitive or traditional meaning (Series and Nilsson, 2018).

It is also clear that the focus has been almost exclusively on legal reforms, which is only one step in the realisation of the rights enshrined in Article 12 CRPD (Degener, 2019). Many questions are still unresolved: there is a lack of examples and criteria to implement Article 12, a lack of analysis of practice outside legal provisions (e.g.: collaborative practices like the Open Dialogue for care decisions made by the person with his/her social network) (Gooding, 2017; ENNHRI, 2020). There is no roadmap to implement Article 12 comprehensively.

Beyond legal capacity reforms, strategies to implement Article 12 should include a broader legal review of family law; but also of medical law; contract law; electoral law; financial regulations – to assess other barriers due to the issue of legal incapacity. The question of access to justice and political participation is also closely linked with that of legal capacity. Still, legislation and policy alone will not change the informal ways in which people are denied the right to have control and a voice in their own lives (Inclusion International, 2014). Collaboration with the medical community, which has an enormous impact on the current system, community support and social networks, awareness raising, as well as support and empowerment of self-advocates, and other strategies for enabling people to have the right to decide go hand-in-hand with strategies for legislative reforms (Keys, 2009; Inclusion Europe, 2008). Accordingly, working towards the goals of Article 12 requires that we recognise the importance of the two interlinked and interdependent paths for legal and social reforms. As argued by the Coalition on Alternatives to Guardianship, the social and legal ramps should be treated with equal importance.

Recent legal reforms have not fully implemented Article 12 and did not really answer to the question on how to move from substituted decision-making to supported decision-making, as both systems still co-exist even in the countries with progressive legislation. The next chapter will explore the academic discourse on Article 12 and scholars attempts to theoretically clarify these concepts.

2 A Narrative Review of the Meaning of Legal Capacity and Supported Decision-Making in Article 12 CRPD

Chapter one explored the policy context, the emergence of the notion of supported decision-making and the reforms efforts to modernise guardianship laws contributing to the text of Article 12, which shows the tensions and controversies the final compromised version includes. This chapter considers the literature exploring the meaning of Article 12 “Equal recognition before the law” and the concepts underpinning legal capacity and supported decision-making for people with disabilities in the context of the CRPD.

Introduction

Following the adoption of the CRPD, scholars focused on the meaning of Article 12 based on the *travaux preparatoires*. Academic attention has been given to the notion of universal legal capacity and the paradigm shift, moving away from a social welfare response to disability to a rights-based approach (MacKay, 2007; Arbour, 2006). Article 12 has been described by scholars with several superlatives: one of the most debated articles during the negotiations (Dhanda, 2007); probably the most controversial article because of its uniqueness in its application in the context of disability (Gooding, 2015); the fundamental precondition for other rights without which they would be meaningless (Quinn, 2011). While the “revolutionary” aspect of Article 12 is celebrated in the literature, scholars have grappled with the meaning of supported decision-making and attempted to define what it means concretely but have also highlighted the need for guidance on how it can be implemented in practice.

More than 10 years after its adoption by the General Assembly, Article 12 continues to raise numerous questions concerning its implementation. According to the CRPD Committee, it is often misinterpreted[36], and it also seems that the countries which have tried to align with Article 12 did not yet succeed.

The adoption of the General Comment No. 1 on Article 12 provoked a new wave of academic articles, critically pointing out the conflicting views of different professions and the need for more concrete guidance to implement Article 12. Scholars’ critical views deplored the incomplete interpretation of Article 12 and the lack of elements of clarification on how to implement this article in practice (Fallon-Kund and Bickenbach, 2017; Craigie et al., 2019). No

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[36] See §3 General Comment No. 1 on Article 12, CRPD Committee, 2014.

comprehensive and clear guidelines exist for a detailed assessment of existing frameworks beyond the general principles of Article 12 CRPD, the broad directions of the General Comment and the all-round recommendations in the CRPD Concluding Observations. The General Comment is silent on how to approach complex situations where people cannot take decisions or when a decision has to be taken on behalf of the person, thereby leaving an absence of guidance on the most difficult cases. It leaves States Parties with many more questions than answers and no concrete suggestions for how to realise the shift from substituted decision-making to supported decision-making. Moreover, there is a general assumption that the meaning of substitute and supported decision-making is clear, whereas the reality is that these concepts are not necessarily clear nor consistently used. This chapter highlights that Article 12 represents a new, values-based paradigm in which people with disabilities have “equal recognition before the law” with a key focus being on the replacement of “substituted decision-making” with “supported decision-making”.

This chapter will draw on a review of the literature to explore 1) how these three terms have been conceptualised in different contexts/by different scholars, 2) what is known about implementing supported decision-making and 3) what are the current gaps in the knowledge base.

Method

A narrative literature review of the academic articles and key policy documents describing the meaning of Article 12 and its concepts of legal capacity and supported decision-making was conducted.

The scope of the review

The review focuses on academic articles and key policy documents written after the adoption of the CRPD by the UN General Assembly in December 2006. The criteria for selection were that literature (a) was published after 2006 and (b) the CRPD was the primary focus or reference framework. The review focused mainly on English language literature but was enhanced by some preliminary research of French and Spanish literature.

The review included key policy documents from relevant European and International institutions or organisations (CRPD Committee, EU Fundamental Rights Agency, Council of Europe), which are references in this area, as well as key policy documents by international Disabled People’s Organisations and Non-Governmental Organisations (e.g.: International Disability Alliance, Inclusion International, Canadian Association for Community Living, Mental Health Europe), which are recognised policy-thinkers in the field.

The review does not include country specific articles, except when the theoretical content is relevant for the review outside the specific legal framework. Similarly, this research contains relevant references on mental health laws as far as they contribute to the exploration of the meaning of Article 12. This narrative review does not seek to provide an analysis of mental health laws, consent to health care or involuntary treatment.

Literature search and selection of articles

The references for this review were identified using three methods: a) electronic search with a combination of key terms (legal capacity, guardianship, supported decision-making, substituted decision-making, capacity law, in combination or not with CRPD/UNCRPD) on academic search engines (Hein, Taylor and Francis, PsycINFO); b) electronic search by key authors' names c) electronic search of policy documents from selected relevant institutions or organisations; d) following up references of relevant articles and publications. 41 references in total have been identified as relevant for this work.

A further scan of the academic literature on the topic was conducted in July 2021 to include more recent articles published during the preparation of this thesis. Another 15 references were added at this stage. These new contributions have been included in this narrative review and the text updated to reflect the current academic debates.

Analysis:

All the selected articles and documents were read and summarised in order to compare their content. A brief summary and notes about the contribution to the meaning of Article 12 and the concepts of legal capacity, substituted decision-making and supported decision-making was made for each article.

The analysis of the articles' content provided recurrent themes around the values-based meaning of legal capacity; the differences between supported decision-making and substituted decision-making; examples of good practices and the lack of theory and practices to implement supported decision-making, especially the "hard cases".

The findings are presented in four sections. Section one explores the meaning of equal recognition before the law, conceptualised as legal capacity. Section two analyses the concept of substituted decision-making and section three the notion of supported decision-making. Section four explores the main gaps and challenges. The last section discusses the implications from these findings for the current research and sets out the research questions to be explored.

Section 2.1 presents the definitions of legal capacity, as a corollary of equal recognition before the law.

2.1 "Equal recognition before the law" – conceptualised as universal legal capacity

Legal capacity is a fundamental concept in law which traditionally helps distinguish decisions that are legally recognised from those which are not. Historically, several groups of people, including people with disabilities, have been deemed "incapable" and denied legal capacity, so their decisions have not been recognised as legally valid (Gooding, 2017). Article 12 now recognises the right to legal capacity for all people with disabilities, as it has been progressively recognised for other groups of citizens. This new paradigm goes beyond the dualistic model of capacity versus incapacity, and the meaning of legal capacity in the CRPD shows this evolution.

Legal capacity – a right reformulated in Article 12

The right to legal capacity *on an equal basis with others* can be found in other human rights instruments which pre-existed the CRPD. The right to legal capacity was first advanced in 1979 in the Convention to Eliminate all Forms of Discrimination Against Women (CEDAW, Article 15) then in the Convention on the Protection on the Rights of All Migrant Workers and their Families (MWF, Article 24). The right to equal recognition before the law can also be found in the earlier Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights (ICCPR)[37]. Article 12 recognises that *all* people with disabilities are equal persons before the law (paragraph 1) and establishes that all people have legal capacity, regardless of their disability (§2). The right to legal capacity in the CRPD is a subsidiary of the right to equal recognition before the law (Gooding, 2015), as it is in the CEDAW.

Legal capacity as *capacity to hold rights* (or legal status – inherent to all human persons) and *capacity to act* (or to exercise rights – legal agency) has been highly debated during the negotiations and is still debated nowadays, as described in Chapter 1. Some authors use the words *legal agency*, to talk about the elements of legal capacity that can be restricted on the basis of disability, which is in violation of Article 12 (2) (Gooding 2017; Arstein-Kerslake and Flynn 2017a; McSherry, 2012). This battle illustrates the resistance of society towards disability and "*brings to the forefront the notion that disability is the last frontier (or at least one of the last) in the struggle for civil rights – framing the issue of*

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[37] Article 16 of the ICCPR as well as Article 6 of the UDHR state that "*Everyone shall have the right to recognition everywhere as a person before the law.*" This right is understood as a right to a "legal personality," which Volio defines as an "individual's 'personhood' in society". Article 16 as adopted did not address the issue of legal capacity to act. Commentaries on the negotiations leading to the adoption of Article 16 do assume that the capacity to act can be restricted. Limitations on the capacity to act do not represent a violation of Article 16.

legal capacity as a right which is accorded to most individuals but which continues to be denied to many people with disabilities" (Flynn and Arstein-Kerslake, 2014a).

A legal opinion on Article 12[38] dated from 2008 and signed by thirty-one experts from around the world reiterated that both elements ("*the capacity to hold a right and the capacity to act and exercise the right, including legal capacity to sue, based on such rights*") are integral to the concept of legal capacity. Eventually in 2014, the CRPD Committee confirmed in its General Comment No. 1 this definition of legal capacity as follows:

> *"Legal capacity includes the capacity to be both a holder of rights and an actor under the law. Legal capacity to be a holder of rights entitles a person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognises that person as an agent with the power to engage in transactions and create, modify or end legal relationships.*[39]*"*

Article 12, however, contains more elements defining legal capacity than previous texts.

Legal capacity - a right extended under Article 12

The use of the term legal capacity with the words *in all aspects of life* in Article 12(2) raises further questions about its meaning. These words "*in all aspects of life*" have been very much discussed. While the CEDAW refers only to civil matters, the scope of Article 12 CRPD is much wider. What then falls within legal capacity? As Series notes, what constitutes an exercise of legal capacity varies according to custom and jurisdiction (Series and Nilsson, 2018). Does that cover only a *legal act*? Significant legal acts are explicitly mentioned in the CRPD: right to marry, entering in a contract, voting, giving consent to a medical act (Arstein-Kerslake and Flynn, 2017a; Series and Nilsson, 2018). However, the relevance of legal capacity is less clear in relation to daily acts: some daily acts can be considered as legal acts (buying bread or a metro ticket, because they constitute a legal transaction), but deciding about what time to get up or about smoking or drinking alcohol are not in themselves legal acts (buying cigarettes or alcohol is, but not its consumption as adults). In some jurisdictions daily legal acts may be protected from being restricted[40] but there is no list of what goes

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[38] Legal Opinion on Article 12 of the CRPD, University of Leeds Disabilities Studies, 21 June 2008, available at: https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/legal-opinion-LegalOpinion-Art12-FINAL.pdf (last accessed 27/10/2021)

[39] CRPD Committee 2014, paragraph 12

[40] See for example the Austrian new legislation or Article 64 of the Czech Civil Code: the decision to limit one's legal capacity does not deprive a person of the right to act independently in

in this category of daily acts. In England and Wales, capacity laws have been regarded as potentially relevant to everyday decisions (Series and Nilsson, 2018). Is the exercise of legal capacity limited to *legal acts* only? Or does the exercise of legal capacity include a more general *right to decide*? In addition, action but also inaction can have legal consequences. Not acting has also been considered as an argument for lack of capacity, because of the important consequences not acting may have (such as debts because of unpaid bills).

From the perspective of the life of people with disabilities, everyday decisions (such as what time to get up, what to eat, or what to wear) are as important as decisions which can qualify for a legal act. This particular point has not really been widely explored in research or academic papers. Arstein-Kerslake and Flynn argued that Article 12 should be interpreted as to protect the decision-making rights of people with disabilities, even when it is not an exercise of legal agency, as a means to curtail traditional relationships of domination (Arstein-Kerslake and Flynn, 2017a). To justify this position, the authors argued that people with disabilities may try to exercise their legal agency more frequently to overcome decision-making barriers. For instance, in institutional or family settings, people may attempt to exert their legal agency (e.g. communicating with noises and gestures to express their disagreement with some situations). Daily decision-making should therefore be protected also outside of legal agency, to utilise the protection of Article 12 in all settings where people with disabilities may be in a situation of domination by others (care staff, family members, etc.) (Arstein-Kerslake and Flynn, 2017a).

Another new element which emerged in the literature about the meaning of legal capacity is its distinction from *mental capacity* and the importance of untangling legal capacity from mental capacity. Mental capacity is used to refer to a combination of cognitive ability, impairment and a person's extent of understanding of the consequences of their actions (de Bhailís and Flynn, 2017). Mental capacity is the criterion traditionally used in many states as a means to assess and deny (fully or partially) legal capacity. Mental capacity can also be referred to as decision-making ability (Gooding, 2017; CRPD, 2014).

Every person has an inherent right to legal capacity (*"legal capacity is a universal attribute inherent in all persons by virtue of their humanity"*(CRPD, 2014)[41]) but all individuals have varying levels of decision-making ability (mental capacity) and these abilities should not have any impact on an individual's right to legal capacity (Flynn and Arstein-Kerslake, 2014 a).

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ordinary matters of everyday life (*Rozhodnutí o omezení svéprávnosti nezbavuje člověka práva samostatně právně jednat v běžných záležitostech každodenního života*).

[41] CRPD Committee, 2014, paragraph 8.

To sum up, the CRPD, in a social justice reading, recognises that the different ways in which people make decisions and different levels of cognitive ability should not be used as a mean to assess and deny legal capacity (Minkowitz, 2010).

The right to legal capacity is not only conceptualised as a right to decide but also as a right to enhance autonomy.

Universal legal capacity - an innovation under Article 12

Legal capacity in a social or human-rights approach goes beyond capacity to act. It is a much more complex notion linked to personhood and autonomy. Personhood is not only the condition of being a human, but it also defines an individual with legal rights, rational thought and moral agency/responsibility in political philosophy. It is in this second meaning that personhood has been denied to people with disabilities, as they have been historically denied these attributes of personhood. This is why scholars have challenged and revisited the notion of personhood, to make it more inclusive (Bach and Kerzner, 2010; Quinn, 2011). And inspired by feminist perspectives on the notion of autonomy, they have framed legal capacity of people with disabilities within the concept of *relational autonomy*.

First, authors have challenged the rationality of individuals by criticising the "*myth system*" of personhood of the liberal democratic political order where the person is defined as being rational, weighs options and risks and decides accordingly (Quinn, 2011). Quinn's vision of personhood embraces a model in which decision-making is seen as a complex and intuitive process reliant on experiences and innumerable supports, which society does not acknowledge (Quinn, 2011). Restrictions of legal capacity therefore amount to not only a denial of rights but also of personhood.

Secondly, autonomy, in the sense of taking one's own decisions freely, can be achieved and exercised in many ways. One way to exercise our autonomy is through the exercise of the right to legal capacity – "*our legal right to enter relationships and agreements with others that give effect to our individual decisions*" (Bach and Kerzner, 2010). Recognising that *autonomy* is *relational* (that is interdependent and interconnected with others) is very important for those who need support and assistance by others in communicating their wishes and preferences, which is often the case for people with intellectual and psychosocial disabilities (Bach and Kerzner, 2010). In the views of the authors, autonomy is formed by social relationships and social determinants: social, economic and political environment (Bach and Kerzner, 2010).

Bach and Kerzner have set minimum criteria for characterising what it means to be an interrelated person (considering that a person is not a rational being):

a) The expression of will and intentions: the expression of choice, desire, goal, with an end, including when the expression of a person's will and intentions can be made by others in cases of behavioural forms of communication
b) Personal identity or a narrative approach: I or someone else on my behalf can render a coherent life story that makes sense, with all the changes, the new directions as well as the discontinuity of a particular life.

Restoring legal capacity, in the sense of personhood and autonomy, gives people with disabilities chances for self-realisation, enables them to flourish. Legal capacity in the equality-based model (Minkowitz, 2007) complements individual autonomy and self-determination. Dhanda describes legal capacity as an equal opportunity to grow and develop (Dhanda, 2007):

> *"With the recognition of universal capacity, there is recognition that, given the opportunity, all human beings can grow and develop. However, for this growth and development to happen, it is important that opportunities be tailored according to the needs of each person. Thus, a claim of equality of opportunity but difference of treatment is mounted. The difference of treatment is advocated so that the universal outcome of growth and development is achieved for all human beings irrespective of race, caste, class, ethnicity, sex, age, or ability.* (p. 458, Syracuse J. Int'l L. & Com. [Vol. 34:429])*"*

Legal capacity constitutes in this sense the backbone of the CRPD, as without the right to decide, many other rights of the CRPD cannot be realised: *"[L]egal capacity to me is a continuum that connects with everything needed to enable to flourish – a right to make decisions and have them respected, a place of one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings. Personhood is broader than just capacity – and these broader connections serve to augment capacity in a virtuous circle."* (Quinn, 2011).

Legal capacity is also both a positive and a negative right: it opens up the space for an expression of the will (positive right) and is a defence mechanism protecting against others who would impose decisions (negative right). Access to support creates a bridge between the two aspects: it brings more information and choice and allows participation (positive right); it prevents intrusion on autonomy (negative right) (Gooding, 2013).

Substantial equality of opportunities to exercise the right to legal capacity is possible with the entitlement to support, when needed (Minkowitz, 2007). The difference must be acknowledged by recognising that each person may need different levels of supports, which allow supported decision-making to be individualised and unique for each person (Dhanda, 2007).

This is why legal capacity is often conceptualised as a continuum of support. Browning and others define this approach as follows: "*It recognises that a person's agency or his or her ability to act within the framework of the legal system is not static but can change over time and in accordance with environmental factors and personal experience*." (Browning et al., 2014). Within the continuum approach, legal capacity remains with the person irrespective of what supports are put in place (Flynn and Arstein-Kerslake, 2011a).

The key question that the moral foundation of legal capacity opens up is therefore not whether the person has capacity but what supports are necessary to enable a person to exercise this capacity (Bach and Kerzner, 2010; Booth Glen, 2012). This applies for all, including for people with high support needs, as this is the only way in which legal personhood remains with the individual – rather than being vested in a third party (Flynn and Arstein-Kerslake, 2011a).

The extended definition of legal capacity allows moving from the dualistic model of capacity versus incapacity to a more complex model recognising the right to autonomy and the right to support. Supports are the tools for advancing personhood, which was previously denied to people with disabilities with the widespread use of substituted decision-making models.

2.2 Conceptualising substituted decision-making

According to the CRPD Committee, support to exercise legal capacity has to replace substituted decision-making (CRPD Committee, 2014). Substituted decision-making can take many forms: incapacitation, guardianship, curatorship, mental health laws (Minkowitz, 2007; CRPD Committee, 2014) are all synonyms for systems where legal capacity is denied to some people and their decision-making is transferred to another person. Substituted decision-making is described as a form of segregation of people who are labelled incapable by an authority and by the society. It divests the individual of his or her right to self-determination and removes him or her from a host of interactions in decision-making with others in society (Salzman, 2009).

The CRPD Committee defines the term "substituted decision-making" based on three common characteristics: 1) removal of legal capacity; 2) appointment of a substitute decision-maker and 3) decisions made in the “best interests” of the person concerned[42].

Reforms of guardianships, as described in Chapter 1, have illustrated the growing concerns around this model and the efforts to re-balance the right of people with disabilities to respect for their autonomy and self-determination, by introducing some individualisation and tailored measures to take into account the abilities and the needs of each individual (Booth Glen, 2012). However, guardianship orders/decisions still prevail unnecessarily and remain broad in scope for several reasons: first courts find it difficult to ascertain the precise areas of decision making with which the individual needs assistance; secondly, partial guardianship still remains based on the fact that the person is incapacitated, therefore there is a tendency to maintain more areas under guardianship – although the individual might be capable of making those decisions if he or she had assistance to do so (Salzman, 2009).

Therefore, as consequences of substituted decision-making, people are not only marginalised, they have fewer opportunities to develop expertise in areas where they might be capable of making decisions and, last but not least, they are stigmatised by the guardianship decision. Salzman calls this vicious circle of loss of autonomy the "*disuse of decision-making powers*" (Salzman, 2009).

Scholars usually describe three traditional categories of models used to restrict legal capacity of people with disabilities, based on their mental capacity:

1. *Status approach*: disability equals lack of mental capacity. There is a presumption of incapacity for persons with a certain disability/diagnosis, who are prohibited from performing specific legal tasks (Dhanda, 2007; Gooding, 2017). It is a labelling process based on stereotypes, irrespective of the skills and the abilities of the person to make decisions (Commissioner for Human Rights, 2012; Flynn and Arstein-Kerslake, 2014a).
2. *Functional approach*: legal capacity determinations are based on a person’s ability to perform a specified task, such as understanding the nature of a contract. Disability alone is not the reason for incapacity, and restrictions of legal capacity are made where necessary, depending on the assessment of the person’s mental capacity (Dhanda, 2007; Minkowitz, 2007; de Bhailís and Flynn, 2017). Limited or partial guardianship is a model which is supposedly tailored to the person’s decision-making ability (Booth Glen, 2012; Gooding, 2017)

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[42] CRPD Committee General Comment No. 1: Equal recognition before the law (art. 12), CRPD/C/GC/1, 11 April 2014, at para. 27

3. *Outcome approach*: capacity is determined by the decisions arrived at by the person with a disability, so where the person makes a "bad" decision they are deemed to lack the mental capacity to make that decision. (Dhanda, 2007; Devi et al., 2011). This test creates a higher standard for people with disabilities than the rest of the population (de Bhailís and Flynn, 2017)

There is consensus in the literature that the status approach and the outcome approach constitute direct disability-based discrimination. The functional approach is however seen by some scholars and law makers as complying with the CRPD and remains largely used in the world (de Bhailís and Flynn, 2017; Series and Nilsson, 2018). The functional approach assesses the person's decision-making ability and the person is considered to lack capacity because of his/her decision-making ability and not his/her impairment. For this reason, some jurisdictions have adopted the functional model, because it maintains a person's self-determination and autonomy by placing limits on a person's right to the minimum extent necessary and it contrasts with the "all or nothing" approach to capacity which is perpetuated by the status approach (Devi et al., 2011). However, although the functional approach at first sight does not seem discriminatory, it can be considered as an indirect discrimination because the decision-making ability test is made on the evidence of an impairment and does not apply *on an equal basis with others* as required by the CRPD (Flynn, Arstein-Kerslake, 2014a). In practice only the decision-making skills of people with disabilities are being assessed. In addition, the purpose of the functional assessment is to determine wherever the person has legal capacity or not. Gurbai describes this practice as discriminatory as "*mental capacity assessments are based on the presumption that adults with disabilities can be protected by imposing restrictions on their legal capacity.*" If that would be a valid assumption for all adults, "*then it should be applied to adults with disabilities and adults without disabilities equally*" (Craigie et al., 2019). The General Comment on Article 12 states clearly that all models evaluating if a person has legal capacity based on diagnosis or using some form of assessment of mental capacity become obsolete under the CRPD and included the functional approach in the list of discriminatory models (CRPD Committee, 2014).

The CRPD Committee has called for the abolition of substituted decision-making regimes and considers that the development of both regimes (substitute and supported) in parallel does not comply with Article 12 (CRPD Committee, 2014). This has important consequences, as it states that the debate is closed: the "compromise" left open in Article 12 not explicitly prohibiting substituted decision-making is seen as problematic both in policy and academic fields

(Craigie et al., 2019). However, the Committee's interpretation has not been universally accepted, with many scholars indicating the need for further research and development of supported decision-making models and disability-neutral criteria (see further sections) to create supported decision-making frameworks.

When it comes to the question of whether or not Article 12 allows for some forms of substituted decision-making and if yes, in which circumstances, there is a wide range of opinions among scholars. Some authors contest the affirmation that the CRPD does not allow for substituted decision-making (see discussions around the genesis of Article 12 in Chapter 1) (Ward, 2011). Some simply posed the question by giving examples of cases asking if a supported decision-making model would work effectively or whether it is realistic to completely avoid substituted decision-making (Salzman 2009, Devi et al., 2011, Werner, 2012). Others clearly adopt the position of a total ban on guardianship and all forms of substituted decision-making (Minkowitz, 2007; Flynn and Arstein-Kerslake, 2014a). For others, if the Convention is to be fully inclusive, supported decision-making is an essential component of this article. In that case, there is no place in a "continuum" of support for substituted decision-making (Bach, 2006). Most authors, however, admit that answers need to be found because there are situations where decisions are being made for rather than by a person – therefore some forms of substituted decision-making would be needed under specific circumstances (Bach and Kerzner, 2010; Gooding, 2013; Gooding, 2017; Booth Glen, 2012; Quinn, 2010; Wayne et al., 2015).

However, there is no consensus on what those circumstances are. Looking at the situation, where a person is at risk of loss of property (e.g.: losing housing or place of living), some authors would argue that this is not a sufficient case for state intervention, if it applies only to vulnerable groups, such as people with disabilities (Flynn and Arstein-Kerslake, 2017b). State intervention should apply in situations where there is risk of harm on an equal basis with others. A legitimate question is should people with disabilities benefit from extra protection, although they have legal capacity on an equal basis with others? One possible alternative to explore is the role of reasonable accommodation to make sure that people with disabilities are treated equally while having access to some form of adjustments. Secondly, there is the question of the prevalence of Article 12 against other human rights. Continuing with the example of the risk of losing property, should Article 12 be superior to Article 28, which guarantees people with disabilities, adequate living standards, including adequate food, clothing and housing? Is it acceptable to lose adequate housing in order to not interfere with the right to autonomy? Reflections on how to address these challenging situations are further explored in section 2.4.

The literature also points at another aspect of denial of legal capacity, which goes beyond formal guardianship and substituted decision-making models. Unregulated exchanges covering a wide range of informal situations can also be considered substituted decision-making. When decisions are made on behalf of the person by families, carers, friends and professionals in the private sphere, substituted decision-making can be informal (Gooding, 2017). Substituted decision-making is not only the formal process of transferring decision-making to another person but it is also an informal practice of segregation of people who are labelled incapable by society.

Article 12 nevertheless builds on the model of substituted decision-making and the different approaches of decision-making abilities and inabilities as the concept of supported decision-making is also defined by what pre-existed i.e. as contrasting to substituted decision-making. Article 12 provides the tool to achieve equality: the right to access support for the exercise of legal capacity. This is usually referred to as the "supported decision-making" model, in contrast to "substituted decision-making".

2.3 Supported decision making

2.3.1 Definition

Several terms are used in policy and academic texts to describe support for people with disabilities to exercise their legal capacity: supports for the exercise of legal capacity, supported decision-making, supports with decision-making and supported decision-making regime or support framework. The use of different terms creates some confusion about what is required by the CRPD (Gooding, 2017), as the meaning of supported decision-making is often very uncertain, not least because it covers a very wide spectrum of possible models (Carney, 2014).

The following paragraphs aim to collate the different definitions provided by academics as well as the CRPD Committee in its guidance for the implementation of Article 12 and relevant concluding observations, (where the Committee has provided recommendations to States Parties on how to implement this article[43]).

Support to exercise legal capacity

The term "support" is not defined in Article 12(3) but in its General Comment the CRPD Committee states as follows: support "*encompasses both informal*

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[43] Countries who have become party to the Convention (States parties) are obligated to submit regular reports to the Committee on how the rights of the CRPD are implemented. During its sessions, the Committee considers the reports of States parties and addresses its concerns and recommendations to the State party concerned in the form of concluding observations.

and formal support arrangements, of varying types and intensity" (CRPD Committee, 2014). The Committee defines support to exercise legal capacity as including a broad spectrum of supports, some of which may engage legal mechanism, some of which may not (Gooding, 2015). The General Comment provides several examples in a non-exhaustive list: advocacy, peer support, information in easy-to-read form, trusted support persons, advance planning mechanisms, alternative communication[44]. This list suggests that the word "support" should be understood as an evolving concept which may include in the future practices that may not have been understood as support yet (Minkowitz, 2007). The idea is that the notion of support for exercising legal capacity will evolve with the time and new models may enter in this category of support in the future.

The meaning of "support" partially overlaps with the term support as a generic term used for people with disabilities, as many forms of support may help them to be more confident and skilled in decision-making. *Supports for the exercise of legal capacity* thus cover a broad range of methods, programmes and adaptations and go beyond the scope of "decision-making".

Supported decision-making

"Supported decision-making" is the term historically promoted as an alternative and also the term used in contrast to "substituted decision-making". The term "supported decision-making" is most commonly used in the literature and in policy documents, including in the concluding observations by the CRPD Committee.

Some authors have tried to define supported decision-making but no comprehensive definition has emerged so far. Some authors have based their definitions of supported decision-making by opposition to substituted decision-making, highlighting key features such as the presumption of capacity (Salzman, 2009).

Mostly two sets of definitions appear – shortly said: supported decision-making as a system, or supported decision-making as a practice.

First, some authors have defined supported decision-making as in a broad sense – referring to a system: Dinerstein attempted to distinguish supported decision-making "*as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual's life*" (Dinerstein, 2012). Similarly, Pathare and Shields define "*organisations,*

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[44] CRPD Committee, 2014, paragraph 17.

networks, provisions or agreement with the aim of supporting and assisting an individual (…) to make and communicate decisions". Kohn's definition reads as follows: "*Supported decision-making occurs when an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behaviour to determine his or her preferences"* (Kohn et al., 2013). But he makes an interesting point showing that supported decision-making is also used for new models that are not "supported". He ascribes that other authors or advocates used this term for situations in which the person being supported has voluntarily entered into an arrangement, such as facilitated decision-making and co-decision-making to describe other versions of supported decision-making. Although described as enabling supported decision-making, these statutory schemes have features that are inconsistent with how supported decision-making is understood given that the ultimate decision-maker is not the person with a disability (Kohn et al 2013). Examples include, facilitated decision-making or advance planning tools by which a person appoints a surrogate decision-maker (*e.g.*, health care proxies and durable powers of attorney). Although bound by the wishes and instructions, Kohn et al. argue that this creates confusion when they are included in supported decision-making.

Further confusion is by created by the fact that supported decision-making "*is referred to as a process, a mechanism, a system, and a framework*" (Browning et al., 2014). There is also some disagreement as to whether it is referring to statutory arrangements alone (where the supporter is authorised to act with the supported person) or to informal support arrangements for decision-making to exercise legal capacity as well (Gooding, 2015).

A conceptual distinction proposed by Browning, Bigby and Douglas is the difference between *supported decision-making* and *support with decision-making*. *Support with decision-making* covers measures to assist people in decision-making outside the direct exercise of legal capacity. They argue that support with decision-making (or decision-making assistance) may include accessible information and personal support in understanding the information, peer support, training. The support with decision-making would indirectly influence the exercise of legal capacity (Gooding, 2017) – as people would have more opportunities to gain confidence and knowledge about decision-making. This allows for a more specific and targeted definition of supported decision making which *"requires the establishment of alternative legal frameworks or the reinterpretation of existing frameworks to allow mental capacity (or the person's decision-making skills) to be seen as broader than just the assessment of an individual's capacity"* (Browning et al., 2014).

However, the notion of "support with decision-making" overlaps with the notion of broader support to exercise legal capacity described in the previous paragraph. But it is important to note that it distinguishes the fact that it has an *indirect* influence on the exercise of legal capacity.

Secondly, some authors refer to supported decision-making only as a practice or an arrangement (which may be formal or informal) where an individual is supported by one or more person(s) to make a decision and communicate it to others (de Bhailís and Flynn, 2017). In most cases, this practice includes the fact that a trusted relationship exists between the supporter and the individual, but there may be exceptions to that principle. The supporters "might help a person to consider the pros and cons of different options, help them to communicate their decision to others, or even help with its implementation" (Series and Nilsson, 2018). Most importantly, the person takes the final decisions – he/she is the decision-maker. This element is also consistent with the proposed definition by Kohn and others.

To summarize, the term supported decision-making means different things for different authors. Most recent academic papers refer to supported decision-making as one practice but it cannot be concluded at this point that is an agreement around this definition.

Accessibility and reasonable accommodation in the exercise of legal capacity

Legal capacity should also be seen in the more general context of accessibility to facilitate autonomy and participation of people with disabilities. State Parties have the obligation to remove the barriers to access the existing information, communication and services open to the general public (Article 9 CRPD). In the context of legal capacity, it could for example include the provision of accessible information of general legal character (about exercising legal capacity), or about banking and financial services. Those would be relevant for a large group of people and therefore fall under the accessibility duty[45]. Reasonable accommodation is defined in Article 2 the CRPD as "*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 CRPD Committee, examples of accommodations may include "*access to essential buildings such as courts, banks, social benefit offices and voting venues; accessible information regarding decisions which have legal effect; and personal assistance."* Accessible

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[45] CRPD Committee General Comment No. 2: Accessibility (art. 9), CRPD/C/GC/2, 22 May 2014, at para. 25

information, but also access to alternative forms of communication and possible adaptations like more time to make a decision, to legally act, falls under reasonable accommodations that facilitate the exercise of legal capacity of individuals. Reasonable accommodation is therefore complementary to the right to support in exercising legal capacity (CRPD, 2014). However, the duty of reasonable accommodation applies in addition and after State Parties have set accessibility standards, which should be gradually implemented (CRPD, 2014a). The duty to provide accessibility echoes the notion of "support with decision-making" but also some elements of the list of broader support listed by the CRPD Committee: *"Support to persons with disabilities in the exercise of their legal capacity might include measures relating to universal design and accessibility — for example, requiring private and public actors, such as banks and financial institutions, to provide information in an understandable format (…) — in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions."* There is a need to clarify the difference between the state obligations to make information and services open to the public accessible, to provide reasonable accommodation and to provide access "*to the support (people with disabilities) may require in exercising their legal capacity*", according to Article 12(3). Further distinction and guidance will be needed to define those terms in the context of legal capacity and the obligations resulting from those.

Supported decision-making regime (support framework)

The CRPD Committee uses the term "supported decision-making regime" to describe the broad elements required to implement supported decision-making as a system (Gooding, 2015). It provides the following definition:

> *A supported decision-making regime comprises various support options which give primacy to a person's will and preferences and respect human rights norms. It 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.). Furthermore, systems of supported decision-making should not overregulate the lives of persons with disabilities. While supported decision-making regimes can take many forms, they should all incorporate certain key provisions to ensure compliance with Article 12* (CRPD Committee, 2014).

These key provisions include: availability to all, even to people with complex communication needs, the right to refuse support and the respect of the person’s will and preferences (CRPD, 2014).

To sum up: “*a supported decision-making regime includes supported decision-making, support with decision-making and broader support to exercise legal capacity, across a range of law, policy and practice*” (Gooding, 2015).

In conclusion, there is no common understanding of supported decision-making and what it entails.

One fundamental and much debated question when considering how to put this right to support into practice is how to access support to exercise legal capacity. In turn this raises the question of how to determine support needs without discriminating on the basis of disability.

2.3.2 How is the need for supported decision-making identified?

To achieve universal legal capacity people must have access to the support that they need to exercise legal capacity. First challenge is the determination of what (if any) support is required - on which criteria should it determined. The second challenge is about people who decline support.

The fundamental question discussed by scholars is how to determine support needs without discriminating on the basis of disability: how can support be assessed in a way that is disability neutral. The CRPD Committee has called for new, non-discriminatory indicators of support needs (CRPD, 2014). But no concrete indicators have been proposed. While there is a consensus about the need to introduce disability-neutral criteria for intervention (Gooding, 2017; Minkowitz, Flynn and Arstein-Kerslake, 2017b), several aspects need to be carefully considered. Decision-making ability tests disproportionally affect people with intellectual, cognitive and psychosocial disabilities, as noted above. They may not only be more affected by the results of the tests (failing the test) but simply by being tested while others are not (Gooding, 2017).

Among the efforts to develop a disability-neutral framework the “Bach and Kerzner model” is one of the most detailed proposals available, where they use assessment of decision-making to determine the type of support a person needs. Bach and Kerzner introduced the notion of “*decision-making capabilities*” to work with the functional diversity of individuals (their mental capacity). The word “capabilities” captures the individual *decision-making abilities* in combination with the obligation to provide *support* (Article 12.3 CRPD) and the obligation to provide *reasonable accommodation* to people with disabilities with decision-making (Art. 3 and 5 CRPD). They propose to shift from the concept of mental capacity to the concept of decision-making capability to maximise the autonomy for people with disabilities, so instead of focusing on the individual, the focus is on the *capability* to function. This model allows everyone who requires support to exercise legal capacity. Three elements form the decision-making capabilities: (1) decision-making abilities (2) appropriate supports and (3) accommodations. The assessment of decision-making abilities may be needed to provide appropriate supports and accommodations to maximise a person's decision-making capability to exercise legal capacity (Bach and Kerzner, 2010).

This model of maximisation of capabilities could also work for people who can make decisions without support and put in place arrangements in anticipation of the times when the person might need support (e.g.: people with psychosocial disabilities or people with Alzheimer's disease) (Weller, 2008).

With this conceptual tool, Bach and Kerzner give a framework to the positive duty of the state to provide access to support in the exercise of their legal capacity, as required by Article 12(3). This model goes beyond the assessment of decision-making ability to access support, as the person's ability can be considered interdependently with the supports available (Gooding, 2017). It means that the person's ability is not limited only to his or her decision-making abilities (the first element), but all three elements noted above (1)+(2)+(3) in conjunction form the person's capabilities.

The Bach and Kerzner model uses decision-making abilities to assess support needs, not to assess legal capacity. However, some questions remain as entering a decision-making capability assessment in itself risks discrimination against persons with disabilities (Gooding, 2015). This raises the question as to how to determine new, non-discriminatory indicators of support needs that comply with the CRPD Committee's requirement of non-discrimination. The literature raises the question of the neutrality of such indicators but does not provide answers or solutions yet.

Secondly, an important distinction needs to be made between situations when support is offered and when support is imposed. What about a person who may need support to exercise legal capacity but refuses? The CRPD Committee stated clearly in its General Comment that support can never imposed (CRPD, 2014). In practice, this principle may have a limit in situations when the person puts herself in danger, can harm herself or may put others in danger. These exceptions to the principle that support can never be imposed will need to be strictly defined for these 'hard cases' (Flynn and Arstein-Kerslake, 2014a). Any limitation however should aim to be disability-neutral to comply with the CRPD. There is currently no consensus or solution as per what kind of limitations and in which circumstances they fulfil this criterion of non-discrimination. This particular point will need to be explored in research and practice, as is further described in section 2.4. below.

People with disabilities have a right to access to support because without support there is no real universal legal capacity (Craigie et al., 2019). This seems at first glance to be in contradiction with the principle of neutral determination of support needs when operationalising it in practice. In theory everyone may be "tested" but would everyone be entitled to support? There is a range of people who may need support in decision-making but would they qualify as a disabled person (disability being an evolving) and therefore benefit from the protection of Article 12? This may require some thinking about it in terms of universal design, policy planning (what available supports exist) and the costs of support which should be at nominal or no costs (CRPD, 2014).

Beyond the determination of support needs, scholars discussed the provision of supports and the question of the statutes of people receiving different support options.

2.3.3 What does support look like?

Support for decision-making varies for each individual – from no support to 100% support on a continuum of support. This raises two important points. First of all, there is the need for boundaries or "dividing lines" between different categories of support, as people will need differing levels of support (Gooding, 2015). However, levels of support should not constitute different legal statuses for the individuals (Flynn and Arstein-Kerslake, 2014a). No matter what level of support along the continuum is provided - that person will still have legal capacity (universally attributed). And secondly, it raises the question of the 100% support at the end of the continuum. Who takes the decision in a 100% support model? The view that decisions sometimes will be made by others and it should be clearly identified as such is shared by many scholars (Bach and Kerzner, 2010; Booth Glen 2012; Quinn, 2010; Wayne et al., 2016). The model of facilitated decision-making is an area often considered by many authors to answer this question.

The Bach and Kerzner's model includes 3 levels of decision-making statuses on a continuum of support:

1. Legally independent (autonomous)
2. Supported decision-making
3. Facilitated decision-making (Bach and Kerzner, 2010)

Each of the statuses implies a particular combination of decision-making abilities, supports and accommodations to be drawn out on a continuum. Each level has a different framework for safeguards. In the first two statuses the person remains the decision-maker, while facilitated decision-making amounts to the interpretation of will and preferences in circumstances where a person is not able to clearly express will and preferences.

Facilitated decision-making is more generally the answer found in the literature to the often-posed coma question (Series and Nilsson, 2018). This question of people in a coma has become the symbolic practical example in literature or policy documents where will and preferences are unknown. Others use the example of 100% support instead. There is consensus that people in these situations, such as coma, are not the decision-maker; this is why authors prefer to recognise that in those situations, the supporter, not the person, is making the decision. (Series and Nilsson, 2018; Booth Glen, 2012; Gooding, 2017; Quinn 2009; Bach, 2009; MDAC, 2013).

Although intuitively facilitated decision-making may resemble substituted decision-making, the term "facilitated decision-making" has been chosen on purpose, to mark a difference from terms used under guardianship regimes. The idea behind it is to highlight the support component (for example by taking into account the history of the person, previous decisions and preferences) and the possibility to evolve on the continuum and work towards supported decision-making. However, some scholars have argued that facilitated decision-making is no different to substituted decision-making – because the model is based on coercive paternalism and may not promote personal autonomy (Devi, 2013).

While the notion of continuum of support and the three points of Bach and Kerzner's model are shared by Flynn and Arstein-Kerslake, they diverge on the status issue and take a critical approach by challenging the functional assessment aspect of the statuses model (three levels of decisions). They argue that individuals should be able to choose the level of support they require and move between the three points depending on the decision and the support available. They consider that otherwise there is a danger of the functional assessment becoming "status contingent" (Flynn and Arstein-Kerslake, 2014a). They have therefore reconceptualised the three points of the continuum of support as interconnected – people may move between points – in an environment providing the "enabling conditions". The enabling conditions include the different tools available for support in exercising legal capacity and accommodations allowing individuals to move from one cluster to another one (Flynn and Arstein-Kerslake, 2014a). These tools include: advocacy, reasonable accommodation, accessible information and communication, recognition of different forms of expression, advance planning tools,…

> *"This conceptualisation recognises that a legally independent decision-maker has an equal right to support in certain aspects of decision-making, as an individual who uses facilitated decision-making has to have the tools to enable greater levels of independent decision-making."*

While the risk of becoming "status contingent" is a real concern, the argument that individuals should be able to choose the level of support they require and move between the points depending on the decision and the support available may collide with the fact that they need support with decision-making – appropriate support may need to be proposed. Further aspects such as methods for participation of individuals in setting up their own support needs and arrangements (from the enabling conditions) could be explored.

The notion of "best interpretation of will and preference"

The CRPD Committee offers a partial answer to the question on how to respond where the individual's preferences are unknown or conflict by introducing the notion of "*best interpretation of will and preference*":

> *"Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations. This respects the rights, will and preferences of the individual (…). The "best interests" principle is not a safeguard which complies with Article 12 in relation to adults."*

The notion of best interpretation of will and preferences has been given little attention in academic debates so far. Skowron attempts to provide guidance on how to understand this notion. He argues that *best* interpretation should not be reduced to *true* interpretation and it should focus on the process of interpretation itself rather than on the outcome (Skowron, 2019). He suggests an inclusive reading of the best interpretation as an everyday process of attention (especially when communication is difficult), because interpretation implies familiarity with the person (Skowron, 2019). This means extending the scope of best interpretation also when it is practicable to determine will and preferences. The risk with interpretation of *true* will and preferences is that conflicts between the *true* or authentic will (in the sense of long-lasting beliefs and desires) and current preferences may emerge (Szmukler, 2017). With true interpretation one could say that this is not free will and impose again the views of another person. At the same time, there cannot be interpretation where things are not known or cannot be known – there can only be presumptions.

This is why the best interpretation should focus on the process itself – where there will be conflicted will and preferences, the interpreter will reach a decision based on what he/she knows about these conflicted will and preferences (Skowron, 2019). It is about presumptions and also about exploring all the options for that person.

Interpretation of will and preferences becomes the standard for ascribing the intention in everyday decisions – in other words legal agency is defined only on the intention (Arstein-Kerslake and Flynn, 2017a). Who is supporting is therefore the key question, as trust, familiarity and safeguards against abuse are fundamental to it.

To provide more content to the notion of supported decision-making and facilitated decision-making, the next section explores existing models of supported decision-making.

2.3.4 Examples of good practice

Initially researchers writing about supported decision making noted the lack of examples of such models to be applied in practice. In recent years, new practices that may be used as inspirations are considered in the literature. Although there is more discussion about existing models by commentators, such discussions tend to focus on the same models with very little analysis.

The Swedish personal ombudsman, introduced in Chapter 1, was first emphasised by the European Commissioner for Human Rights. It is often quoted as an interesting practice example for people with psychosocial disabilities (Minkowitz, 2007; Salzman, 2009; Devi et al., 2011; Pathare and Shields, 2012; Booth Glen, 2012; Morrissey 2012). In the field of psychosocial disability, advance directive is also presented as an immediate and available model which can give a response to decisions about health care treatment (Weller, 2008). Similarly, the Open Dialogue model from Finland is used for care decisions which are made with the personal input of the individual concerned, together with wider networks of their choice (Morrissey 2012; ENNHRI, 2020; Gooding, 2017). The British Columbia Representation Agreement is the other example often quoted in the literature for people with intellectual disabilities (Salzman, 2009; Devi et al., 2011; Booth Glen, 2012; Pathare and Shields, 2012; Morrissey 2012; Gooding, 2015).

While these examples were developed prior to the CRPD, most authors do not really bring arguments regarding what makes these models interesting and how they work in practice and how they answer to the challenges of Article 12.

Many more reforms are being implemented in different countries but have not yet been the object of an academic review or analysis. The periodic reports to the CRPD Committee offer some resources about the situation and the legal reforms in different countries (Dinerstein, 2012). Generally speaking, there is no analysis of the law in conjunction with its implementation and practice in countries where reforms have taken place.

There seems to be an untapped amount of information to research on, based on current reforms on legal capacity but also on formerly existing models, which have not really been studied in depth (Kohn et al., 2013).

A number of non-statutory initiatives can be found in more recent books or reports (such as, for example, FRA, 2013; Gooding, 2017; ENNHRI, 2020). It is interesting to note that good practice examples are now presented as one element of a system of supported decision-making, rather than one model which would fulfil the criteria for the system. The focus has clearly moved from legal reform only to a wider spectrum of formal and informal measures.

Piers Gooding's book chapter entitled Practical Examples of the CRPD Support Framework in the Mental Health Context explores several practices and measures to operate Article 12 (Gooding, 2017). It is important to note that most of the practices and examples presented are outside of the mental health legislation, probably because so far there are no legal frameworks which operate with Article 12. It includes advance planning, both as formal and informal practice, supported decision-making pilot projects, family-based and collaborative practices, as well recovery-oriented practices, trauma-informed services, and other consensual means framed in the social and human rights models of disability. More fundamentally, this chapter shows that many examples related to community-based services have their place in a support framework, as they enhance effective support and self-determination (Gooding, 2017).

The lack of clarity of the concept of supported decision-making and the lack of good practices show that there are many gaps and challenges related to the implementation of Article 12, for which there is little or no answer.

2.4 Gaps and challenges

There is so far limited research on theory and practice related to supported decision-making. Five main challenging topics and gaps in research can be identified from the literature. The first two challenges are overarching issues in the debate about Article 12: how to operationalise Article 12 and how to ensure the participation of people with disabilities. Three other recurrent subthemes emerged: how to make sure that supported decision-making is also available to people with high support needs, how to provide support for the “hard” cases, people who are at risk of harm to themselves and to others and the specific issues around mental health and criminal justice and forced treatment. This section will not provide answers to all these questions but pinpoint the different arguments developed and the gaps identified by scholars.

Limited operationalisation and lack of implementation of supported decision-making

Because of the limited operationalisation and lack of implementation of supported decision-making, there is a lack of evidence base. In addition, there is a lack of comprehensive guidance, for which the CRPD Committee was criticised, as it did not solve all the ambiguities and questions raised by the implementation of Article 12 in its General Comment (Gooding, 2015).

There has been general agreement that there is a lack of empirical research and literature about supported decision-making and its implementation (Salzman, 2009; Morrissey, 2012; Werner, 2012; Pathare and Shields, 2012; Kohn et al., 2013; Kohn and Blumenthal, 2014; Browning et al., 2014; Carney, 2014; Carney and Beaupert, 2013; Gooding 2015). There have been calls for research that identifies and evaluates processes, practices and outcomes of supported decision-making (Kohn et al., 2013; Kohn and Blumenthal, 2014) as well as research that develops theoretical approaches (Browning et al., 2014). No evidence is available in the literature about the quality of the decisions and the benefits in the life of people with disabilities, besides the intrinsic value to decide for oneself (Devi, 2013). No quality-based evidence of supported decision-making from a process and outcomes point of view can be found in the literature (Kohn et al., 2013).

In terms of operationalising Article 12, some broader steps or general directions towards reforms are mentioned in the literature. Those include legal changes, policies and programmes to implement the new legislation, including the recognition and availability of non-statutory and informal arrangements (Gooding, 2017). Systematic reviews of discriminatory laws (many areas are affected by the issue of legal capacity: criminal law, medical treatment, mental health law, property law…) are also mentioned as an essential step (Series and Nilsson, 2018; Bach and Kerzner, 2010; Flynn and Arstein-Kerslake, 2014b). The system change should begin with the assumption that all individuals have a decision-making ability (Flynn and Arstein-Kerslake, 2014b) – this is often referred to in the literature as the principle of *presumption of capability*.

A system of safeguards to avoid abuse and coercion also needs to be in place. But again, there is no comprehensive list of safeguards to implement. The role of supporters in the process of decision-making is an area where more evidence is needed, to determine what is "ordinary" influence (in the sense of normal traces of influence of the supporter), undue influence, abuse and coercion. This influence cannot be ignored in the process of supported decision-making. Key issues mentioned by scholars are conflicting will and preferences between the supporter and the individual (Bach and Kerzner, 2010); conflicts of interest and undue influence by supporters (Salzman, 2009; Devi et al., 2011; Kohn and Blumenthal, 2014; Kohn et al., 2013). A clear definition of undue influence is needed. The dilemma noted by Series is "that *by definition* where a person is subject to undue influence, the authenticity of any expression of their will is compromised" (Series and Nilsson, 2018). Another aspect is risk taking, not only needed at the individual level (mitigate risks with each individual) but it should be seen in the context of safeguards to prevent abuses (Gooding, 2013).

The issue of resources is also often mentioned in the literature as a key concern (Salzman, 2009; Kohn et al., 2013; Series and Nilsson, 2018). Because of resources constraints, the emphasis could be on family and community supports rather than professionals, formalising natural support networks and community (Pathare and Shields, 2012; Gooding, 2017). The cost issue is a valid concern, even more pressing since support should be available at nominal or no cost to persons with disabilities (CRPD, 2014).

Possibly the most difficult issue in relation to the implementation of Article 12 is the CRPD Committee's view that parallel systems (introducing supported decision-making in parallel with substituted decision-making) are not permitted. The co-existence of both systems is presumed to find viable alternatives, as this takes time because of the numerous challenges. The Committee, however, has turned this path down without offering alternative solutions.

Supported decision-making for people with very high support needs

The reference to 'very high support needs' is intentionally broad to cover people who may not understand what a decision is, may not be able to express preferences and are often seen as having no will, in the sense of a clear desire (Cole, 2015). Personal stories and practices show that supported decision-making is possible for people with very high or total support needs: "*Even with all the tools available, Charlie still cannot express his choices independently. We do not always know what he wants, decisions are not always perfect, but together we can support him to make decisions about where he wants to live or what he wants to do*" (Inclusion International, 2014). The question is how to recognise the decision-making of people with severe and profound disabilities: *"They are people who, intellectually, would never be able to understand what a decision was, why it had to be made or what its reasonably foreseeable* *consequences would be yet, ironically, they (my son included) make dozens of personal decisions every day of their lives solely from their experiential knowledge of life as they know it. Just watch them!"* (Cole, 2015)

Another frequent example is about those in a coma, or those who have no connection to any form of support, no communication in place (Booth Glen, 2012). The question, as posed earlier, is how to provide the necessary support to all persons irrespective of their disability so that they can participate to indefinable degrees in the decision-making process. This includes the legal recognition of personalised support and accountable process that can be put in place in this person's life to ensure that the decisions to the benefit of the person would reflect, to the greatest extent possible, the will and preferences of the person. Because of the very high level of individualisation and personalisation of the support, the accountability of the process is an important issue which needs to be explored.

Personal stories of people with high support needs illustrate that decision-making can be supported within chosen and trusted relationships. This raises the question of how and from whom can support be provided in the absence of family and friends, especially for people who have been institutionalised and have no such natural support but only paid staff in their life. While expanding support networks is a recognised activity, there is too little information in the literature about the availability and about the sustainability of the support networks (Pathare and Shields, 2012).

Another aspect related to people with high support needs is the potential use of intention only to qualify legal agency – intention understood as the expression of personhood and will and preferences and which can be interpreted or can be translated in a concrete action (Arstein-Kerslake and Flynn, 2017a). This extended protection of Article 12 is justified in the eyes of the authors by the disproportionate domination people with cognitive disabilities faced and the threats to their exercise of legal capacity because of the situation of dependence (Arstein-Kerslake and Flynn, 2017a). This is why they argue that legal agency can be exercised just with the intention (this could apply for examples in home or family settings where a person communicates with his/her body or actions the wish to leave the home or the house). "Any *indication that there was purpose and deliberation behind a particular action, decision or omission, should be considered sufficient evidence to ascribe intention*" (Arstein-Kerslake and Flynn, 2017a). While this raises many practical questions of interpretation of the wishes, considering the intention as legal agency allows extending the protection of Article 12 to redress the situation of people with disabilities in unbalanced relationships.

People with disabilities at risk of harm

Another challenge often raised in the literature is about people at risk of harm to themselves or others. The main challenge is how to operationalise supported decision-making in situations of risk such as harm or self-harm. When is state intervention acceptable in the context of the CRPD? Supported decision-making throws new light on non-discrimination provisions and support in this context (Gooding, 2013). For people with psychosocial disabilities, the focus should be on supports to maximise and maintain their capacity, including arrangements for periods of incapacity (Weller, 2008).

Some scholars have paved the way for more guidance on how to deal with these cases. It is about setting the right boundaries without allowing the exceptional to again become the rule. It is also important that the framework for a support model of legal capacity is not entirely based on these extreme cases (Flynn and Arstein-Kerslake, 2014a).

The Bach and Kerzner model uses the notion of *serious adverse effect* to tackle challenging situations, including the case of placement in a psychiatric facility. *"A situation of serious adverse effects occurs when a person, as a result of his/her actions or those of others:*

- *experiences loss of a significant part of a person's property, or a person's failure to provide necessities of life for himself or herself or for dependants; or*
- *experiences serious illness or injury, and deprivation of liberty or personal security; or*
- *has threatened or attempted or is threatening or attempting to cause physical and/or psychological harm to himself or herself; or*
- *has behaved or is behaving violently towards another person or has caused or is causing another person to fear physical and/or psychological harm from him or her."* (Bach and Kerzner, 2010)

In addition, they propose safeguards based on choice, dignity and integrity; reducing and changing the responsibilities of doctors as well as making community resources (services and supports) available (Bach and Kerzner, 2010).

Flynn and Arstein-Kerslake have proposed a more restrictive model. They suggest that a proportionate state response is required to protect the person's human rights in case the person *is at risk of* ***imminent and grave*** *harm to their life, health and safety (*Flynn and Arstein-Kerslake, 2017b). Their model of state intervention is narrower than the previous model, which in their argumentation does give a "very broad justification for intervention" and does "not adequately balance the individual's dignity of risk with the legitimate state impulse to protect its citizens from exploitation and abuse" (Flynn and Arstein-Kerslake, 2017b). The authors have explored models that are disability-neutral to propose a permissible state intervention on an equal basis with others, making parallels with state intervention in the case of domestic violence. However, they focus on intervention at the request and with the consent of the endangered party. While the approach of the vulnerable adults model may not meet the non-discrimination criteria of the CRPD, the question is how such model of state intervention can meet the needs of people with disabilities: would the criteria "at the request and with the consent of the person" provide the necessary protection for persons with disabilities in a situation of crisis or with no communication (or communication that very few people understand)? Exploring the role of the right to reasonable accommodation might guarantee that neutral criteria will not disproportionally affect people with disabilities.

Mental health related issues

In considering the implications of Article 12 and the challenges regarding legal capacity, the mental health sector has a very important role to play. Several mental health legal provisions are related to the issue of legal capacity and will need to be considered and reformed in the light of Article 12. It includes mainly mental health laws, including involuntary psychiatric intervention and treatment and some provisions of criminal law (like the insanity defence or unfitness to plead). These special defences refer to disability-specific exceptions to typical legal processes – the person cannot be held culpable for a particular act (insanity defence) or cannot, because she/he lacks capacity, have representative capacity (unfitness to plead) (Gooding, 2017). The CRPD challenges these provisions by guaranteeing legal capacity to all in all areas of life. Because they are based on disability these provisions are usually also considered discriminatory, like guardianship laws (de Bhailís and Flynn, 2017, Minkowitz, 2007). The question again is how to recognise the specific needs of people with psychosocial or intellectual disabilities, while recognising their full legal capacity. Legal capacity is an essential component of access to justice – to have legal agency to exercise the legal rights the person has. At the same time, the justice system should be more responsive to disability-related needs and provide accommodations in police, courtroom and prison processes and environments. It is outside the scope of this work to look at the provision of procedural accommodation and appropriate support (like justice intermediaries). However, the challenges in implementing Article 12 include the reform of a body of laws related to legal capacity. And it poses the question of how to guarantee legal capacity in all areas while providing the appropriate support to people with disabilities.

In relation to psychiatric intervention and treatment, several scholars criticise the competition of rights and a certain superiority of Article 12 over other rights, such as the right to the highest attainable health care (Art. 25) or the right to life (Art. 10) (Freeman et al., 2015). Dissenting voices about Article 12 put the emphasis on other rights and values, such as respect and autonomy but also dignity, safety and the right to life (Craigie et al., 2019; Plumb, 2015). Graham Morgan's personal reflection about being considered capable and responsible for oneself when suicidal and his happiness now, after he was helped or Scott Kim's examples about making a treatment decision in a case of delirium which led a person to believe that doctors are impostors (Craigie et al., 2019) illustrate the complexity of the debate, the competition between differing human rights standards and the unique experience of each individual. They argue that the question is not about having or not having capacity but about providing sufficient options, resources and improving support to live to cover the broad aims of mental health laws.

As presented in the sections above, there are numerous unanswered questions, to which scholars just open the way for further discussion and research. One way of determining system changes is indeed by exploring the experiences of people with disabilities and involving them in shaping the new system and its limits.

The role and participation of people with disabilities in shaping supported decision-making

The issue of participation of people with disabilities has been given little attention in the literature about legal capacity. The involvement of disabled people's organisations in the negotiations has been highlighted and described by several authors, some of them living with a disability (Schultze, 2010; Dhanda, 2007; Minkowitz, 2015; Kayess and French, 2008). Although many reports highlight that persons with disabilities should be involved in the drafting of new legislation (a requirement under the CRPD Article 4(2)), they do not suggest how this is to be achieved. For example, the large participation of people with disabilities in the reform in Austria (see Chapter 1) has not been considered in academic study.

This narrative review also observes that the literature focuses more often on people with psychosocial disabilities than on people with intellectual disabilities. This may be due to fact that some researchers themselves are people who have a lived experience of psychosocial disability. Many articles (outside of those used for this review) are therefore looking at the consequences of supported decision-making on mental health laws. No author however has yet directly included people with intellectual disabilities or psychosocial disabilities in his or her research on legal capacity at this point.

Among people with intellectual disabilities and their representative organisations, the report "Independent but not alone" includes several contributions provided by group discussions, personal stories of self-advocates about their capacity, about taking their own decisions, how they want to receive support and the fact that they want their decisions to be respected (Inclusion International, 2014). Some tools have been developed, such as facilitation guides to organise Discussion Groups on the right to decide[46].

The VOICES project[47], realised by the Centre for Disability Law and Policy in Ireland, is one example of the involvement of people with disabilities (intellectual disability, autism, dementia or an acquired brain injury) in academic research. Fourteen personal stories from 12 countries cover four thematic areas related to legal capacity – criminal responsibility, contractual capacity, consent to medical treatment, and consent to sex and relationships. Personal stories and legal and policy responses were used to discuss these topics.

No example of systematic participation among people with psychosocial disabilities could be found in the narrative review. Some elements appearing in the literature show frequent dilemmas among this group of people: what may be a positive experience for one person may not be for another one. A member of a community of people with psychosocial disabilities describes from his point of view the contradiction around compulsory community treatment ("probably keeps me alive") and the fact that "there is limited evidence that this form of intervention is effective" (Craigie et al., 2019). Other service users claim to have different experience (Craigie et al., 2019). These points of view raise the question of the representation of people with disabilities and the range of service user voices and survivors of psychiatry in the discussions about legal capacity.

The diversity of the views of people with intellectual and psychosocial disabilities on the issues of legal capacity should be widely acknowledged and pursed as one of the key elements of supported decision-making reforms. Plumb has called for "*more collective dialogues*" among service users and survivors and "*to pull together our considerable insights and experience into clear demands where none of us feel overlooked*" (Plumb, 2015). It raises the

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[46] https://inclusion-international.org/wp-content/uploads/2013/08/Discussion-Group-Facilitaros-gude.pdf (last accessed 20/10/2021)
[47] https://ercvoices.com/ (last accessed 27/10/2021)

question about how to capture and reflect in law reform, policy and planning the diversity of the views and experiences of people with disabilities.

All these five areas point act the fact that empirical research is needed to provide answers and an evidence base to the main gaps and challenges related to a comprehensive implementation of Article 12.

2.5 Discussion

This review shows that there is an important and growing number of articles about legal capacity, especially after the publication of the General Comment No. 1, which provoked many reactions, overall rather critical. It reflects the importance of the topic in the academic and public policy fields. While authors point out that the CRPD has created an impetus for change, they highlight that research on supported decision-making is in its early stages, as many aspects must still be discussed and defined. The General Comment provided some clarification but failed to take into account many comments made in response to the draft General Comment (Craigie et al., 2019). The current knowledge and understandings about supported decision-making - what it means and how it can be implemented is under constant development.

This chapter highlights that Article 12 represents a new, values-based paradigm in which people with disabilities have “equal recognition before the law” aiming at the replacement of “substituted decision-making” with “supported decision-making”. However, the meaning of these terms is unclear and the path to implementing Article 12 appears to be rather complex and challenging if it is to guarantee universal legal capacity for all people with disabilities.

The academic literature explores the moral foundations of Article 12 from a human rights and social justice approach, thus building a strong set of arguments, which constitute the backbone of Article 12. Achieving equality is a long journey, many strongly rooted beliefs and long-lasting imbalanced structures of power need to be looked at when exploring the notion of legal capacity of people with disabilities.

However, the concept of “supported decision-making” is inconsistently used in different contexts (Browning et al., 2014) and there is no consensus about the definitions in the literature. The notion of supported decision-making should be refined and a clear answer to the question of whether the CRPD does allow for some forms of substituted decision-making and in which circumstances needs to be answered. Many scholars with different nuances agree with the evidence that in some situations, decisions are made for a person and not by the person. Not admitting this would remove credibility of supported decision-making

(Browning et al., 2014). The delicate balance between autonomy and protection is probably the most controversial point and the discussions among scholars show that consensus may be extremely difficult, given the complexity of the issue.

Scholars underline the importance of developing empirical research and call for model testing to provide evidence about how supported decision-making works in practice and how this model can be implemented. This review shows that, so far, no comprehensive set of recommendations has emerged from the narrative review about what needs to be done or steps to build a system of supported decision-making.

Pilot projects and legal reforms have not yet been the object of in-depth academic study, but the analysis of their content, practice and outcomes may be beneficial to provide evidence on how supported decision-making could be implemented. Several aspects could be clarified with empirical research.

First of all, research is needed to explore the accountability of the process to clearly define the border between supported decision-making and substituted decision-making to avoid supported decision-making operating in practice as de facto guardianship for some people (Carney and Beaupert, 2013; Salzman, 2009). More research in how everyday decisions and more complex decisions (living arrangements or health care treatment) operate in practice will provide evidence on accountability for the decisions made, for the decision-making processes and outcomes. Research should also help in identifying what methods allow supported decisions based on the will and preferences of the person from the perspective of decisions processes and outcomes.

Research should also explore ways to recognise in legal terms the interdependence of the person with his/her supporters, to make supported decision-making a (legal) tool that is recognised universally. It is important to guarantee that the legal capacity of people with disabilities is not being questioned for each decision. To enjoy legal capacity on an equal basis with others, the legal capacity of people with disabilities should be recognised in conjunction with support(s) and reasonable accommodation.

The definitions of disability-neutral criteria and of the right to reasonable accommodation in the context of legal capacity need to be accurate and empirically tested to offer more responses. An evidence base is needed in terms of disability-neutral methods to assess support needs – which methods can qualify to be non-discriminatory. Reasonable accommodation is in theory seen as complementarity to the right to support but there is no clear distinction between the two. Research should explore and define what supports the right holder is entitled to under Article 12(3), what supports are covered under the right to reasonable accommodation and the duty of accessibility in the context of legal capacity. Another area to be explored is how to move from the notion of vulnerability to a notion that is embedded in a human rights approach to disability. And if at all, what role reasonable accommodation can play in offering an alternative to the notion of vulnerability.

There is a significant research gap in the notion of developing decision-making skills and experiences. The conceptualisation of legal capacity as a continuum approach, allowing people to move depending on their abilities for specific decisions, implies the possibility to develop and improve one's decision-making skills. How to ensure that people with disabilities but also their supporters access at an early stage tools and methods to develop and improve decision-making skills; how people with high support needs can be empowered to participate and take decisions. This aspect of capacity-building or empowerment would be one of the practical steps to make the "opportunity to grow" a reality.

This question brings up the important issue of the provision of services and resources available in the community (Craigie et al., 2019). The opportunity to grow, to flourish, cannot happen if the focus in implementing Article 12 stays at the level of a legal reform. Support for decision-making is linked with empowerment and access to services and resources. This needs to be acknowledged as it is crucial for a comprehensive implementation of Article 12. At the same time, research should explore the dividing lines between (social) supports and support for decision-making (Carney and Beaupert, 2013) – which support is specific for decision-making. Again, this needs to be clarified in order to specify the obligation to provide access to support under 12(3), and therefore what support measures are available at no cost or nominal cost. The existence of social supports is a broader issue but may influence supports for decision-making, both in terms of quality and accessibility.

Last but not least, the involvement of people with disabilities in empirical research about decision-making is an important aspect of the implementation of Article 12 and of the general principles of the CRPD. Pilot projects may provide an evidence base of user-led project activities.

An evidence base, supported by empirical research, should then be confronted with the philosophical and moral foundations of Article 12 described by scholars, to guarantee that practice is in line with these principles.

Based on these findings and gaps in research, we will look at a selection of pilot projects focusing on the practical aspects of support, how support is determined and provided and scrutinising the new developments and outcomes of pilot projects, as an element of empirical research. The objective is to collect a quality evidence to analyse how the findings of pilot projects can be reflected in the academic discourse as well as policy and legal framework of countries working on the implementation of Article 12.

3 Features and Outcomes of Evaluated Pilot Projects

The narrative review highlighted the need for empirical research about supported decision-making and the lack of models and practices. In particular, scholars pointed out the sparse data about who uses agreements of supported decision-making, who supports and what the outcomes are both in terms of process and in terms of decisions (Kohn and Blumenthal, 2014). This chapter considers the data and outcomes available from the external evaluations of pilot projects that were established with the aim of implementing Article 12 CRPD. Such an analysis has not been undertaken before. The objective of this chapter is therefore to identify common elements that could be used as a basis for evaluate future Art 12 projects. In 2017, a total of 25 pilot projects were identified in 18 countries around the world by the researcher[48]. Only four of them were identified in 2017 as having a publicly available independent evaluation report published during and after the project implementation. Very few of the existing projects have been externally evaluated.

This chapter includes the three sections. Section one presents the main facts and findings of each of the four evaluated pilot projects and then summarises commonalities and differences of pilot projects features.. The second section looks at the lessons learned and limitations. Implications for further research are explored in the last section. The characteristics of pilot projects participants are presented in Annex No. 1.

3.1 Pilot project facts and findings

Four pilot projects have been implemented and evaluated in three countries: Israel, the United States and Australia (South Australia).

3.1.1 Article 12 Supported Decision Making Pilot – Israel

Background

The "Article 12 – Supported Decision Making" project was established by the Israeli organisation Bizchut[49] – an independent human rights organisation, whose ongoing work on this issue was already important[50]. Bizchut ran the first pilot on supported decision-making in Israel from September 2014 to October 2015. The project intent was to restore people's control over their own lives

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[48] This number is based on the author's own research on pilot projects and available material shared by the Open Society Fund, funding pilot projects implementing Article 12 in the world.

[49] See Bizchut's website: http://bizchut.org.il/en/ (last accessed 25/1/2017)

[50] Between 2014-2016, Bizchut has given more than 90 lectures and training sessions on the issue to about 3,000 persons with disabilities, family members and professionals, including family court judges. Bizchut has established and advanced a coalition of 20 organisations to push for reform of the Guardianship Law and recognition for supported decision-making in Israel.

through an effort to develop a model for supported decision making and conduct a pilot to examine the efficacy of the model by providing support in practice (Bizchut, 2017).

The project tested the hypothesis that all persons with disabilities can benefit from *"independence support services"* which will help them fulfil their independence and autonomy with full legal capacity[51].

People

22 participants with a wide range of disabilities took part in the pilot project: 11 people with intellectual disabilities, 8 people with psychosocial disabilities and 3 people with autism. Three participants dropped out during the project.

The project involved a mix of people under guardianship and people who had full legal capacity. Eighteen of the participants had a guardian at the beginning of the pilot (nine guardians being family members), while four of them did not (a guardian was appointed to one of the four later on).

The pilot team was composed of the staff of Bizchut and volunteers, both acting as supporters (11 persons in total). The project worked only with supporters who were trained to do this job and who did not have previous trusted relationship with the participants. One supporter worked with one person.

Activities

Supporters underwent initial training including eight sessions with four 45-minute units each (before the pilot). Practice and individual counselling sessions were provided to the supporters throughout the year (Bizchut, 2017).

Four criteria were put in place for participation in the pilot. 1) Participants must be over 18; 2) They are already or soon to be under guardianship; 3) They must reside in Jerusalem or its vicinity; 4) They must be motivated to receive support in order to advance their independence in decision-making (Bizchut, 2017). The reason to recruit people under guardianship, or at risk of becoming so, was to demonstrate that the supported decision-making model is an alternative to guardianship. After an introductory meeting, potential participants were interviewed and a "matching" supporter was proposed to them (Bizchut, 2017).

The process of support included weekly one- to two-hour meetings between the person and the supporter. On average, each participant attended 30 support meetings throughout the year. Supporters reported about each meeting.

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[51] See the executive summary of Assessment Study Findings presented by Tal Kahana and Dr. Shira Yalon-Chamovitz December 2015 available at http://bizchut.org.il/en/wp-content/uploads/2016/03/21_12-Kenes-2015-EXECUTIVE-SUMMARY-eng-press.pdf

They tested supported decision-making informally without legal instrument, in all areas of life, including finances.

Meetings with family members have also been organised to discuss the project advancement and become familiar with the notion of supported decision-making.

Evaluation methods

The objective of the assessment report was "*to examine the extent to which the support process contributed to an increase in the participant's level of independence in making decisions*" (Kahana and Yalon-Chamovitz, 2015)

The method used is a comparative study before and after based on a selection of indicators: the degree to which pilot participants understood the significance of the decision-making process, the extent of their desire and inner motivation for independence in making decisions and the extent of their actual independence in making and implementing decisions.

Two rounds of one-to-one interviews were conducted (pre-pilot interviews and interviews at the end of the pilot) with 10 out of 12 pilot participants interviewed at both stages.

The assessment study analysed the participants' answers (including direct quotes) about their expectations and goals regarding support, their decision-making (understanding, independence, types of decisions). The authors also analysed the differences between participants and guardians in perception of participant's level of independence in making decisions, based on six pairs of participant-guardian interviews. The supporters were also asked to list the main challenges of the support process from their perspective.

Main findings:

The study concludes that the pilot significantly advanced the participants' ability to understand decision-making processes, their decision-making skills and other soft skills. The authors observed that three types of changes occurred among interviewees that they attributed to the supported decision-making process:

1. internal changes: improvement in various stages of decision-making processes and skills (self-advocacy, improvement of money management)
2. changes related to guardianship: more confidence in the relationships, more independence. For six of the participants, procedures were launched for the removal of the guardian

3. changes related to the participant’s contact with external actors (successful experience, personal ambitions fulfilled resulting in more self-confidence) (Kahana and Yalon-Chamovitz, 2015).

Recommendations

The assessment report gives a set of recommendations mainly focused on continuing the development and the use of the model (expanding the pilot and extending its duration). The authors draw attention to the need to adapt the model to people whose function fluctuates. They highlighted the need to bring more actors on board, to look at support into the overall arrangements involved in the lives of persons with disabilities (Kahana and Yalon-Chamovitz, 2015). They underlined the importance of better defining of the role of the supporter (not a friend, not a carer, and how to work with the person’s expectations) and of guiding supporters in the process as well as strengthening family support and their involvement in the model (Kahana and Yalon-Chamovitz, 2015). From the training courses insights, the parents wished to receive more information, tools and a sympathetic ear to their questions/opinions (Bizchut, 2017).

The authors of the assessment report note that the number of guardians who were interviewed for the evaluation report (two only) is low and that the study does not fully reflect their perspective (Kahana and Yalon-Chamovitz, 2015).

Finally, Bizchut highlighted in its model description that support people with disabilities receive from their services is usually partial and insufficient. Support is time consuming, intensive and requires training which the supporter does not have. “*Hence, it should be emphasised that the development of supported decision-making services cannot replace the development of a personal support package*” (Bizchut, 2017).

3.1.2 South Australian Supported Decision Making Project

Background

The South Australian Supported Decision Making trial was conducted by the South Australian Office of the Public Advocate[52], a statutory state agency, in partnership with the Julia Farr Association MS McLeod Benevolent Fund with a view to implementing a new model of service delivery to facilitate supported decision-making arrangements, consistent with Article 12 CRPD. The trial was planned in two phases from June 2011 to November 2012. The first phase was intended to test the applicability and refine the service model while the second phase broadened the implementation of the refined service model.

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[52] About the work on supported decision-making by the Office of the Public Advocate and the pilot project: http://www.opa.sa.gov.au/resources/supported_decision_making (last accessed 25/1/2017)

People

Phase 1 of the project was approved for up to 15 participants and phase 2 was approved for 20 participants (Wallace, 2012).

The pilot involved people with brain injuries and people with intellectual disabilities as the second largest group and then people with autism. Recruitment criteria included no psychosocial disability as first diagnosis, no experience of abuse and no significant conflict with family and friends (Wallace, 2012). All the participants made the decision to be part of the project themselves (Wallace, 2012).

Twenty-six agreements on supported decision-making were adopted during the project. Supporters included friends and immediate family members, but in most cases there was only one supporter per person (OPA, 2012).

Activities

The South Australian trial aimed to assist people with a disability who wanted support in decision-making: 1) to set up an agreement with important people in their life, 2) to provide this support, and 3) to monitor the operation of the agreement. The model of the trial provided a "non-statutory supported decision making agreement". The pilot considered health care, accommodation and lifestyle decisions but did not cover decisions about finances and assets.

The participant's roles are described as follows: "*The person needs to be able to:*

- *Express a wish to receive support*
- *Form a trusting relationship with another person(s)*
- *Indicate what decisions they may need support for*
- *Indicate who they wish to receive support from and for which decision*
- *Express a wish to end support if that time comes*
- *Be aware that they are making the final decision and not their supporter (take responsibility)*

The decision supporter needs to:

- *Respect and value the supported person's autonomy and dignity*
- *Know the supported person's goals, values and life experiences*
- *Respect the individual decision-making style of the supported person and recognise when and how support may be offered*
- *Form a trusting relationship with the supported person*
- *Be willing in the role of supporter, to fulfil their duty to the supported person, and not use this role as a way of advancing their own interests or any other person's interests*
- *Be able to spend as much time as is required to support a person to make each decision*

- *Assist in the expression of that decision to others if required*" (OPA, 2012)

The template of the supported decision-making agreement is a very simple document written in easy language. It includes the names of the persons (supporters, supported person), a description of how the person wants to be supported (in terms in presenting information, discussing good and bad things, telling his/her wishes to third persons) and the areas of decisions where the person wants the supporter to help in making decisions. If the person was under guardianship, basic information about the guardianship order was also included[53]. Participants ticked all the four areas of life which can be included in the agreement and added specific areas where they wanted to receive support, such as court proceedings, travel, parenting, family relationships or medication.

In terms of supported decisions which happened during the pilot, that of the health decisions taken treatment, hospitalisation and medication were the most frequent. One notable decision involved moving to independent accommodation with community-based support. Decisions about relationships, work and holidays were the most common lifestyle decisions (OPA, 2012).

Because the agreements ended with the pilot project, an exit strategy for the project participants was individually developed.

Evaluation methods

For Phase I of the project, an in-house evaluation was undertaken by the Project Control Group, a group of experts in different areas including people who have a lived experience of disability. An external independent evaluator was then appointed for the trial proper Phase II.

Evaluation of Phase I – preliminary in-house evaluation

Phase I of the evaluation intended to test the applicability of the trial approach. This evaluation focused on the steps taken to set up the supported decision-making arrangements, so looked at the description of the agreements rather than the operation of the agreements.

The report observed that participants gained confidence, as the agreement is strengths-based and does not focus on deficits and gaps. Preliminary observations about the process include feedback on how people felt about using the agreements, e.g. signing the agreement was a positive life event for pilot participants, about the agreement being used for specific decisions, including in health care decisions (e.g.: for surgery). One important observation was that

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[53] See the agreement template as an annex of the evaluation report.

supporters were not able to maintain diaries, which aimed to track the supported decision-making process.

Independent Evaluation of the South Australian Supported Decision Making project

The independent evaluation covers the two phases of the Supported Decision Making Project. It aimed to assess three aspects of supported decision-making:

- How well the new model of supported decision-making is being implemented and delivered, if its anticipated benefits have been met and to identify unanticipated consequences.
- The outcomes and specific benefits of supported decision-making for people with disabilities in relation to inclusion, autonomy and personhood.
- The experiences and perspectives of people with disabilities regarding the impact of supported decision-making on their lives.

The evaluation report is based on quantitative data and qualitative data (interviews, observations from project meetings attended by the evaluator and project material). The evaluator interviewed 53% of participants, 27% of supporters, and staff from three service provider organisations.

Main findings:

The evaluator reported that the project had delivered benefits to most of the participants. Those benefits include self-confidence in the decision-making process, decision-making skills and other soft skills as well as *"a clear growth in personal empowerment and self-determination"* (Wallace, 2012).

The evaluator also reported about the issue of having control over their money to achieve goals and the frustration of some participants about the extent to which their wishes were or could be achieved if they had more financial independence (Wallace, 2012).

Supporters also noted benefits: they reported about increased adult interaction and positive changes in interpersonal relationships – family members and friends change their perceptions when acting as supporters. Tensions between participants' families and supporters are described as an issue when it comes to the implementation of a decision (Wallace, 2012).

From the perspective of participants' service providers, the evaluator reported the development of interpersonal skills, financial management skills, as well as the improvement of relationships, self-confidence and the fact that it opened up new opportunities in the life of some participants – it restored power within the person (Wallace, 2012).

The evaluator also talked to some project participants who did not go ahead with a supported decision-making agreement. The reasons for not doing so vary from a supporter declining the request to take over this role to the fact the person thought she didn't need it.

The evaluator described the difficulty in recruiting participants from the Alternative to Guardianship stream[54] – only three people instead of the twenty planned reached a supported decision-making agreement. Initial referrals did not meet the project recruitment criteria around consent. Another factor may have limited the recruitment in this stream: people under guardianship are more often isolated and did not have family members or friends to act as supporters (OPA, 2012).

In addition, the evaluation report pointed out the confusion about the differences and the potential overlap between supported decision-making and guardianship. The concerns about risks and the non-statutory supported decision-making agreement were questioned by guardians. The evaluator concluded that important advocacy work would have been required by the project co-ordinator to succeed in recruiting more people under the Alternative to Guardianship stream. At the same time, Wallace pointed out the need to reconsider how to identify users of supported decision-making within the structures of guardianship (Wallace, 2012).

The evaluator concludes that the project "*has demonstrated that Supported Decision Making can work alongside guardianship, and that people using Supported Decision Making can demonstrate that they no longer require a Guardianship Order.*" (Wallace, 2012)

Recommendations

The evaluator recommended developing a change strategy for further expansion of the service model and its implementation.

She also pinpointed the role of peer work in supporting recruitment. This includes for example the issue of providing training and support to supporters. It also raises the issue of people who are socially isolated and access to volunteers who could take up this function, when no supporter is available (Wallace, 2012).

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[54] The project originally planned to have two streams of 20 people each: an Early Intervention stream (for young adults or people who recently have been diagnosed as having an acquired brain injury for example) and an Alternative to Guardianship stream for people who would otherwise be under guardianship.

3.1.3 Supported Decision Making Programme, South Australia

Background

This project, run by the Health and Community Services Complaints Commissioner[55] (HCSCC) South Australia, an independent state agency, took place a few years later (2014-2015), as a follow up from the earlier South Australian pilot project presented in the previous section. The project aimed to train workers in disabilities agencies (*facilitators*) to establish and facilitate social support systems that support people with disabilities to make decisions. The project was demonstrated to improve quality of life and community engagement for participating people with disabilities (Community Matters, 2015).

People

The model proposed by HCSCC is centred on the "decision maker", and one or more supporters, preferably drawn from the decision-makers' natural networks rather than paid workers (Community Matters, 2015).

The original project plan was to involve 24 decision-makers, 24 supporters, as well as 12 facilitators (workers in disability services/agencies). In total, only 7 decision-makers, 8 supporters and 5 facilitators (8 participated but only 5 completed the programme) participated.

No characteristics of the participants can be found in the project documents or in the evaluation[56]. Some participants were under guardianship[57].

Activities

The project activities aimed to build capacity of people with disabilities and of supporters to access support to decision-making, understand options, consequences of a decision, and develop skills in decision-making. That included working on decisions made by and reflecting the expressed wishes of the participant with disabilities rather than what was perceived to be in the person's "best interests" (Community Matters, 2015).

Facilitators had to support selected decision-makers to choose their supporters and provide ongoing support to those supporters (some of whom had to make significant shifts in previous beliefs and behaviours to be able to operate as a supporter). They also had to facilitate meetings involving the decision-maker

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[55] For the work of HCSCC on supported decision-making see http://www.hcscc.sa.gov.au/hcscc-supported-decision-making-project/ (last accessed 25/1/2017)

[56] See a brief project description at http://www.hcscc.sa.gov.au/wp-content/uploads/2014/10/HCSCC-Overview-of-SDM-Project.pdf (last accessed 27/11/2021)

[57] Four persons were under guardianship by deduction from the number of consents to participate in the interviews for the evaluation report.

and their supporters to choose the decisions they wanted to make and to assist with implementation (Community Matters, 2015).

No information is available about the types of decision or the decision processes which happened during the pilot project.

Evaluation methods

Five evaluation objectives are pursued:

1. Determine the circumstances in which the project model is and is not effective.
2. Identify the outcomes of the project for decision-makers, supporters, facilitators and organisations.
3. Identify the circumstances in which, and mechanisms by which, positive outcomes are or are not achieved, for decision-makers, supporters, facilitators and organisations.
4. Determine the effectiveness, strengths and weaknesses of the training and mentoring processes for trainee facilitators and recommend improvements.
5. Develop recommendations for the further development and sustainability of the project. (Community Matters, 2015).

For the evaluation report, interviews or focus groups were conducted with 21 people from these three groups as well as managers of the organisations (Community Matters, 2015). Interviews with decision-makers have not been conducted by the evaluators but by a facilitator not involved with a particular person in the project. Because of the small number of participants, the evaluators have not assessed quantitative data but only qualitative data.

Main findings:

Six decision-makers out of eight[58] claimed to experience positive changes in their lives: increased confidence, greater control over their lives, being able to set goals and dreams they would not have expressed in the past, more interaction with the community, less frustration and anxiety. By gaining more autonomy in their life, an increase in their well-being and their skills (e.g. money management) improved (Community Matters, 2015).

Supporters also reported positive outcomes to a lesser extent, highlighting the fact that it is a challenging position to fulfil. In some cases, they said that their relationship had improved and they felt happier about it.

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[58] One participant withdrew from the programme – this is why in total only 7 decision-makers completed the programme.

Facilitators reported that they learned new skills (especially "listening for meaning") and started working differently with all their clients and not only project participants. The new practice influenced the work of the whole organisation, also in terms of risk management and community involvement. One facilitator's quote in the report is particularly eloquent: "*I think the biggest change [decision maker] had, was that he was able to speak up for himself, say things that he would have never done in the past. The wishes that he expressed were absolutely unknown to the service*." (Community Matters, 2015).

The evaluators note that several mechanisms worked well: intensive training for facilitators (6 days in total), mentoring facilitators (self-reflection and emotional support) and the role of community of practice (creating social capital by exchanging peer stories, success or similar issues).

On the other hand, other mechanisms should be improved: five out of eight decision-makers had difficulty in recruiting one key supporter. Supporters (including family members) reported three to ten hours of work per week without counting project meetings.

The evaluators described the programme as accessible for decision-makers with sufficient capacity: "*the project has clearly demonstrated that many people with disabilities have much greater capacity than had previously been assumed*." The evaluators are sceptical about the fact "*that it could work for all people in all circumstances*" based on the evidence that facilitators mentioned the selecting out of people because of their lack of capacity (Community Matters, 2015)[59].

The evaluators concluded that the programme creates a supportive environment in the services (Community Matters, 2015).

Recommendations

In relation to the difficulty in recruiting supporters, the evaluators proposed a back-up strategy with a pool of volunteer supporters, who could step in when there is no supporter. Or they suggested that the client should first go through a befriending programme before entering the supported decision-making programme (Community Matters, 2015).

The evaluation report noted repeatedly that the time involved in the process of supporting the decision-making was higher than planned and that coordination and communication have been challenging. For this reason, the evaluators recommended using diaries to keep records of time, workload, which activity is time consuming. With these data available and recorded, staff and budget

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[59] From the description in the evaluation report, no person with severe disability has been involved in the project.

issues could be better planned. The evaluation report pointed out the difficulty to coordinate and to organise meetings (decision-maker, supporter and facilitator with additional persons outside) due to several constraints, mainly the lack of staff and service organisation (Community Matters, 2015).

Several recommendations are made to undertake economic studies, an independent cost-benefit analysis, analysis of social return on investment (quality of life), a business plan, a marketing strategy as well as a long-term funding strategy (including the question of a fee from clients). At the same time, the evaluators proposed a strategy to use trained staff to become mentors and facilitators as well as trainers, to make the best use of the staff who have acquired new skills and experiences (Community Matters, 2015).

Overall, the evaluators of the HSCC supported decision-making programme recommended that “it should be continued and expanded” and called for further research to refine and expand the practice (Gooding, 2017).

3.1.4 Centre for Public Representation and Nonotuck pilot project, Massachusetts

Background

A 2-year pilot project was run by the Centre for Public Representation, a disability rights non-profit law firm, together with the Nonotuck Resources Associates, a service provider of residential support (shared living and adult foster care residential supports)[60]. The project had two over-arching goals[61]: (1) Maximise individuals’ independence (by directing their own decision-making process and making their own decisions) 2) Identify best practices and factors that can be replicated as models that advance supported decision-making as an alternative to guardianship.

This pilot project was, at the start, the first one in the United States – during the project other states passed legislation on supported decision-making and another five pilot projects were funded – and so the pilot’s purpose was to contribute to operationalizing supported decision-making in the US.

People

The pilot project included 9 participants with intellectual and developmental disabilities, all from Nonotuck service provider. Three participants were under guardianship.

Multiple supporters were chosen by the project participants (from 2 to 10) – supporters are characterised by their long-term relationships with the

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[60] Website project: http://supporteddecisions.org/ (last accessed 25/1/2017)

[61] See: http://supporteddecisions.org/pilot-project/how-we-did-it/ (last accessed 25/1/2017)

participants (the minimum length of a relationship was 3 years) as well as the type of role in their lives (family members, friends, care managers, caregivers). It is important to note that participants could choose whether supporters act jointly or separately.

Activities

The project staff developed an easy-to-read version of a supported decision-making agreement for the pilot project, as the first version was very legalistic. The final reviewed agreement included an accessible format with a font with size 14 points, a section noting how the person expresses and conveys preferences and what she/he wants; specific areas for decision consultation assigned to each designated supporter; specific areas for decision consultation to be excluded; and a section on how supporters should cooperate with other supporters (if more than one supporter for a certain type of decision) – jointly or separately (Pell and Mulkern, 2015). The supported decision-making agreement contained 6 categories to define the scope of consultation for each decision: Finances, Health care, Living arrangement, Relationships/social, Employment, Legal matters and Other (to be specified).

Nine adults signed a Representation Agreement, which was then notarised to have legal standing. The signatures were followed by a celebration.

In total, the nine adults took 72 supported decisions during the pilot project, as reported in the following table, mostly utilised for health care and financial decisions. The decisions taken during the pilot ranged from everyday choices to very important decisions, such as surgery, relationship (having a child), switching bank or changing one supporter.

SDM Decision categories	Number of decisions (3/2015 – 7/2016)
Health care and dental care	17
Financial	15
Social and leisure	13
Employment/Volunteer/Day supports	10
Relationship	7
Legal matters	4
Living arrangements	3
Mental health/Behavioural health	2
SDM arrangement decision	1
Total SDM decisions	**72**

Table No. 1 Number and categories of supported decisions

Safeguards incorporated in the project were: no cost, voluntary adoption, free legal assistance, withdrawal from the pilot at any time for any reason, and care manager monthly monitoring.

Evaluation methods

The objective of the evaluation was to identify challenges and recommendations to inform broader supported decision-making use.

The report for the first year focused on the establishment of the pilot (partnership, staff, planning, communication and management, advisory council, evaluation) and the process of selecting participants, supporters, areas of supported decision-making assistance and completing agreements. For the first-year report, interviews were conducted with CPR staff and Nonotuck care managers. The evaluators observed monthly project team meetings and advisory council calls.

Data collection for the second-year report included observation of project coordination and events as well as interviews with project participants (all the 9 SDM adopters, 15 of their supporters, care managers and CPR staff). The second-year report focused on the experience of using the agreement and the impact, identifying challenges related to the implementation and more practice recommendations.

Main findings:

The evaluators found that participants understood that supported decision-making means making their own decisions and receiving support when they want help. All reported that it is a positive experience and that they were satisfied with the process of providing decision assistance as well as the decisions made. The evaluation findings showed that the multiple supporters model worked well – also because arrangements for regular communications were already in place before (Pell and Mulkern, 2016).

The project impacted on the skills of decision-makers: pride, self-confidence, more control over their life as well as a feeling of happiness (Pell and Mulkern, 2016).

The evaluators also highlighted the positive impact on supporters, especially family members who were trying to move from a parent role to a supporter role. Supporters understood and were able to uphold their duties to assist an individual with disabilities to understand options, help the person express preferences, and honour the person’s preferences and decisions. The evaluators pointed out concerns about safety: parents have themselves reported to the evaluators about their ambivalence and the fact that they may have limited the options to those considered “safe” in some decision processes. It raises the question of risk-taking and the issue of the right balance between support and safety (Pell and Mulkern, 2015; Pell and Mulkern, 2016).

Evaluators noted that participants did not report experience abuse, neglect or financial exploitation through use of supported decision-making. Many pilot participants stated their belief that the structure of the agreement, selecting people one trusts to help with decisions, and having more than one decision supporter, reduces risk of abuse (Pell and Mulkern, 2016).

The evaluators found it useful to establish a partnership between a legal advocacy and a service provider organisation, which share common values, for setting up supported decision-making.

The evaluators also took note of the limitations of the pilot: (1) it involved only people with intellectual and developmental disabilities who had cooperative social networks; (2) the Nonotuck experience with shared living and adult foster care models offered a favourable environment for supported decision-making - those without family involvement could find supporters through the service to which they belong; (3) all participants used spoken language and no people with severe or profound disabilities were involved. The evaluators thus concluded that the study benefited from very positive conditions for piloting supported decision-making (Pell and Mulkern, 2016).

Recommendations

The recommendations coming out of the evaluation reports offered substantial structured practical advice for further projects, collating what worked well and what could be improved.

One area to be explored is peer support and opportunities to share experiences with other supporters. Establishing learning communities of supporters, locally and nationally, could provide for greater awareness of issues that arise for supporters, and more comfort that supported decision-making is a sustainable alternative to guardianship (Pell and Mulkern, 2016)

Preventing problems and risky situations had been a concern in the project pilot: evaluators suggested periodic reviews of supported decision-making values and principles with both supporters and decision-makers as well as in-person visits by staff. For this, guidance for assessment and monitoring would need to be created.

The evaluators recommended expanding experiences in banking, managing funds, and for those receiving publicly-funded services, to self-direct their services and regularly review the need for a representative payee (Pell and Mulkern, 2015; Pell and Mulkern, 2016).

The report also looked at the response by community members where relevant. Only a few decisions involve community members – in most cases reaction by third parties was positive and responsive after the supporter's instruction and guidance. The role of supporters in enhancing communication has been favourable. But the evaluators noted that it is important to include interactions with third parties to avoid negative experiences with third parties (Pell and Mulkern, 2016).

In terms of costs and staff costs, the evaluators also pointed out the extra time needed for many activities with families or supporters and people with disabilities. They also indicated the need for sufficient resources for the two years. For example, 2,892 direct staff hours were needed for preparation work and the first year (1 September 2013 to 30 August 2015): 1,190 hours for CPR staff and 1,702 for Nonotuck (Pell and Mulkern, 2015).

To sum up, these four projects from different places in the world presented common features and some differences, which are summarised in the final section.

3.1.5 Summary of the pilot projects features: commonalities and differences

This chapter shows that all the pilot projects are small scale – both in terms of the number of people with disabilities involved and in terms of the length of the projects, which lasted no more than two years.

In terms of participants, the projects involved predominantly people with intellectual disabilities, mainly people with mild and moderate intellectual disabilities. There is no evidence that people with severe and more profound disabilities have been involved.

Another common feature regarding project participants is the fact that the project involved a mix of people under guardianship or similar court order restricting their legal capacity and people who have full legal capacity. The legal statutes of project participants may have evolved as some of them went through restoration of their legal capacity during the pilot. This feature was seen as crucial for demonstrating that supported decision-making model is an alternative to guardianship.

In terms of supporters, three out of the four projects worked with natural well-known supporters: family members, friends and care staff. Only the Israeli project involved supporters who did not have a previous trusted relationship with the participants. With the exception of the US pilot, participants often chose one supporter.

Three out of the four projects used a type of supported decision-making agreement. In all but the US project the agreements only last for the duration of the project.

Pilot projects showed a number of common features, but also presented similar lessons learned and limitations.

3.2 Lessons learned and limitations of the pilot projects

What are the lessons learned that are transferrable for future pilot projects based on the main findings and the recommendations made by independent evaluators?

3.2.1 Lessons learned

First of all, all the evaluation reports stated that, overall, the realisation of pilot projects have been a positive experience and had a positive impact on the participants.

All reports unanimously highlighted the positive effects for participants in terms of decision-making skills, confidence in taking decisions and in terms of empowerment and self-esteem. They also pinpointed the (often) positive impact on supporters – better understanding of how to support the person, better listening to him/her, better relationships – and family members gained a better understanding of how to steer their sons and daughters towards more independent decision-making.

An important lesson learned is the vast need for training, re-training, information as well emotional support for supporters. Sufficient initial training is essential but evaluators pointed out the need for constant training and support over the project and suggested providing mentoring or coaching to supporters as well as organising peer support groups, as possible good practice.

Similarly, the same continuous need for support and exchange is highlighted for facilitators who also need mentoring and the possibility to share experiences in a learning community.

The importance of training and support is linked to the question of what good support looks like or, phrased in other terms, how to deal with choices and risk taking and how to respect the values of supported decision-making. Supporters need time to adopt the new paradigm of wishes and preferences and understand how it differs from the “best interests” approach. While this is not always explicitly mentioned in the reports, concrete elements (e.g.: lack of time, training needs, building experience and learning from different decisions) illustrated that this cannot be achieved over the length of a pilot project, it is a long process.

In terms of areas of support and decisions, pilot projects do not distinguish a legal act from personal decisions without legal consequences. Nor is this question explored by the evaluators. It shows that from a practical point of view and because agreements need to be accessible to those who use them, this issue was not relevant in the implementation of the pilot projects.

In addition, evaluators of both South Australian pilot projects noted that planned decision-making diaries were not kept, although they would consider this aspect as a good practice. The overview of decisions taken in the US pilot project shows that information about the nature and the process of decisions gives useful data about the utilisation of supported decision-making.

One key lesson learned is about supporters for people who are socially isolated or experience difficulties in recruiting supporters. The experience of the Israeli project which worked with external supporters shows that it could be a viable alternative for those who don't have a network. The experience was rather short but the findings on this short period are similar to those of the other projects. Evaluators all suggest creating peer support opportunities or programmes.

All the evaluation reports recommended expanding the pilot for more participants as well as to other groups at risk of guardianship and for a longer period of time. Where the pilot was conducted within services, there is the question of the offer of a kind of supported decision-making programme to all their clients.

Last but not least, the evaluation reports described in more or less detail the issue of time involvement: they pointed out the underestimation of working hours of project staff (and the need to readjust the number of participants) and of the time spent in meetings with people with disabilities and their supporters. The commitment of staff participants has been a key factor of success but to replicate pilot projects more regular meetings and sufficient staff time need to be budgeted.

While the pilot projects have a number of good practice to share, their small scale both in terms of participants and in terms of time limits their impact and possible replication.

3.2.2 Limitations

While there was an effort to involve different people in terms of age in the projects, one of the biggest limitations is the fact that no people with severe and profound disabilities have been involved and the scarce involvement of people with psychosocial disabilities. The first South Australian pilot project excluded people with psychosocial disabilities. No real explanation is given for that. The second South Australian project excluded people with lower capacity – as the pilot participants are described as having "sufficient capacity". In general, the pilot projects worked with people who had a network and potential supporter(s). The experience of creating or expanding a network, for people who do not have such a network, has not been an element of these pilot projects[62].

The second biggest limitation is the lack of information and evaluation about the process of decision-making and implementation of decisions. This may be due to the short length of the projects – there was not enough time to monitor how the agreement works in practice and collect a number of decisions, or because decision-making diaries were not kept. However, the example of the US pilot, which systematically reported the decisions made, shows that even in a shorter period a sample of everyday and more complex decisions in different areas of life were recorded.

In addition, decisions about finances and assets which are the object of a specific paragraph in Article 12 CRPD to underline its particular importance were not included in the first South Australian pilot[63].

In relation to the implementation of the decision, pilot reports did not have the space in most cases to monitor third parties or community reactions. Those are important to test the viability of supported decision-making as an element of the system of supported decision-making. Again, to demonstrate that supported decision-making can be an alternative to guardianship, experiences with implementation of decisions and third parties acceptance will be necessary.

Another aspect which is completely absent from the pilot projects' evaluations is the issue of reasonable accommodation or adjustments for people with disabilities who need support in decision-making. No mention of any accommodation need was found in these reports. The projects looked at how the person wants to be supported (in terms in presenting information, discussing good and bad things, informing third parties of his/her wishes) but no offer of reasonable accommodation seems to have been proposed as part of

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[62] The Israeli project worked with a pool of staff and volunteers who were not part of the individuals' networks but they did not work on expanding natural networks.

[63] From the second Australian report; it seems that money management may have been included in some agreement. This deduction is based on the description of the outcomes on decision-makers (e.g. pp. 20-23)

the agreement nor in connection with a specific decision (when recorded or described). This may be partly due to the level of capacity of the participants of the different projects; however, the right to benefit from reasonable accommodation for decision-making should also be explored and tested.

Another limitation is the objective of the pilot projects and of their evaluation, which is influenced by the organisations that run the project. In Israel, the project was run by a human rights organisation – independent from social services and state agencies, campaigning for guardianship reform. In the US, the project was run by a non-profit law firm focusing on disability rights and a service provider offering community residential supports, thus the success of the pilot cannot be separated from the value-based principles already existing in these services. In Australia by contrast, the two pilot projects were run by a statutory state agency and by an independent state agency with the view to delivering supported decision-making as a programme from the service delivery perspective.

More broadly, the pilot project evaluations lacked information and analysis about the implications for a systemic change in law and practice. It poses the question of how pilot projects can contribute to law reforms. The evaluation reports do not identify the elements to be “worked out” or translated in legal terms; nor do they evaluate how to combine and recognise the agreements in their respective legal orders. To demonstrate that supported decision-making can be an alternative to guardianship, clear guidelines, recommendations and safeguards for law and practice should be drawn from the pilot projects. This implies that the partnerships could have to be extended to include the right mix of actors and stakeholders who can analyse and transpose pilot results into systemic guidelines and recommendations and can formulate demands in an adequate way.

Finally, the pilot projects are not critically looked at from the perspective of their compliance with the CRPD. It would be crucial to check the different aspects of each model with the principles of Article 12.

3.3 Implications for research

The evaluations of pilot projects confirm in practice the intrinsic values of supported decision-making in terms of empowerment and the importance of choice and control in people’s decisions. The first findings tend to confirm the assumption, described by Kohn and others, that if wishes and preferences are respected, decisions should be more beneficial in terms of autonomy, dignity and self-determination (Kohn et al., 2013). The pilot projects’ findings and recommendations also confirm the need for more research and more trials in the field, as they only pressed open doors. While the reports establish positive findings, more arguments are needed to affirm that supported decision-making is a viable alternative to guardianship. Only the evaluation report of the South Australian pilot project states that supported decision-making is a viable alternative to guardianship (Wallace, 2012). The universality of the model has not been proven yet by pilot projects although they claimed to demonstrate universal legal capacity for all based on Article 12. Further supported decision-making experiences with people who do not use verbal communication and people with severe and more profound intellectual and psychosocial disabilities will be required to demonstrate that supported decision-making can be an alternative for all. Similarly, further supported decision-making experience with people who do not have any support will be required to guarantee the accessibility of it to all.

The material collected by the evaluators shows the need for systematic data collection – a clear list of data for evaluation purposes should be defined. Data should include relevant participants' characteristics and detailed records of the decisions, decision processes and results (the implementation of decisions), including community/third parties' reactions. It includes recording the use of reasonable accommodation in decision-making as an instrument for one specific decision or for several decisions. Simple but efficient recording formats should be designed, to avoid overloading supporters or facilitators. One aspect which is not mentioned in the reports is the outcomes of the decision: to analyse how wishes and preferences are respected and to assess the quality of the decisions made (Kohn et al., 2013; Kohn and Blumenthal, 2014). Pilot projects have assessed the satisfaction with the overall process, the decisions and the support received. More in-depth qualitative instruments will be needed to analyse how wishes and preferences are respected. Such an analysis may be limited when interpretation of will and preferences is required when a person cannot express will and preferences.

The narrative review in Chapter 2 shows that many authors have attempted to identify how to move towards this new system through pilot projects. Carney made a first attempt to look at those in Australia. He points out the small-scale and short-term characteristics of the projects and their limitations (Carney, 2014). He throws a light on problems with recruiting volunteers, conflicts between supporters and guardians as well as the lack of effectiveness of facilitation tools. He concludes by saying that "*the preliminary findings from the pilots serve to reinforce the urgent need for an independent, medium-term, comparative study, which would evaluate different models in different jurisdictions.*" (Carney, 2014).

Pilot projects on the implementation of Article 12 should be the object of scientific study in a comprehensive and comparative way. Each pilot, although with similar aim, took place in a different country, with different categories of participants, different sub-objectives and with different means, financial, personal and others, for its realisation. Therefore, comparing and analysing projects from an international research perspective would be useful.

In the two previous chapters exploring academic papers as well policy and legal reform trends, the discourse focused mainly on the system level and law reforms. Most supported decision-making pilot projects were tested at the individual level in a real environment but without direct connection to a legal reform or system change. There seems to be a disconnection between the pilot projects – looking at individual support needs and the principles for law and policy reforms that were exposed and discussed earlier in this thesis. The next chapter seeks to reconcile the individual and the global level. It proposes arguments to create a framework to analyse all the levels (micro, mezzo and macro) needed to operationalise legal capacity for all, as guaranteed in Article 12 CRPD.

4 A Framework for the Analysis of Pilot Projects

The introductory chapters have highlighted the need for further clarification of the concept of supported decision-making. The narrative review also highlighted the lack of empirical evidence regarding how support is provided, by whom it is provided, as well as decision processes and outcomes. The literature and policy documents put an emphasis on necessary legal reforms to comply with Article 12 and the recognition of full legal capacity, while the evaluated pilot projects focused on day-to-day decisions, individual planning and empowerment as well as social work with people with disabilities and their supporters. But the analysis of evaluated pilot projects did not provide enough elements that could be used for comprehensive analysis of further pilot projects.

With a view to filling this gap and reconciling the legal and the social aspects, this chapter proposes a tool for analysing pilot projects, to facilitate the collection of information on how pilot projects can contribute to the implementation of Article 12 in day to day practice. It also seeks to clarify some conceptual features of Article 12.

The aim of this chapter is therefore to set a specific framework for the analysis of the pilot projects. The framework builds on recommendations and steps for reforms that have been identified in the different documents concerning Article 12, mentioned earlier in this work, such as strategic papers from NGOs, DPOs, academic articles, conceptual policy papers by different "thinkers" as well as the evaluation reports previously mentioned.

The framework will provide a prism through which the pilot project data and results can be considered and compared. The framework attempts to reconcile all the levels of actions needed to operationalise Article 12: the micro, mezzo and macro levels. At the same time, the framework was developed from the point of view of an individual, taking for granted that supported decision-making is conceptually a person-centred model.

4.1 A person-centred framework

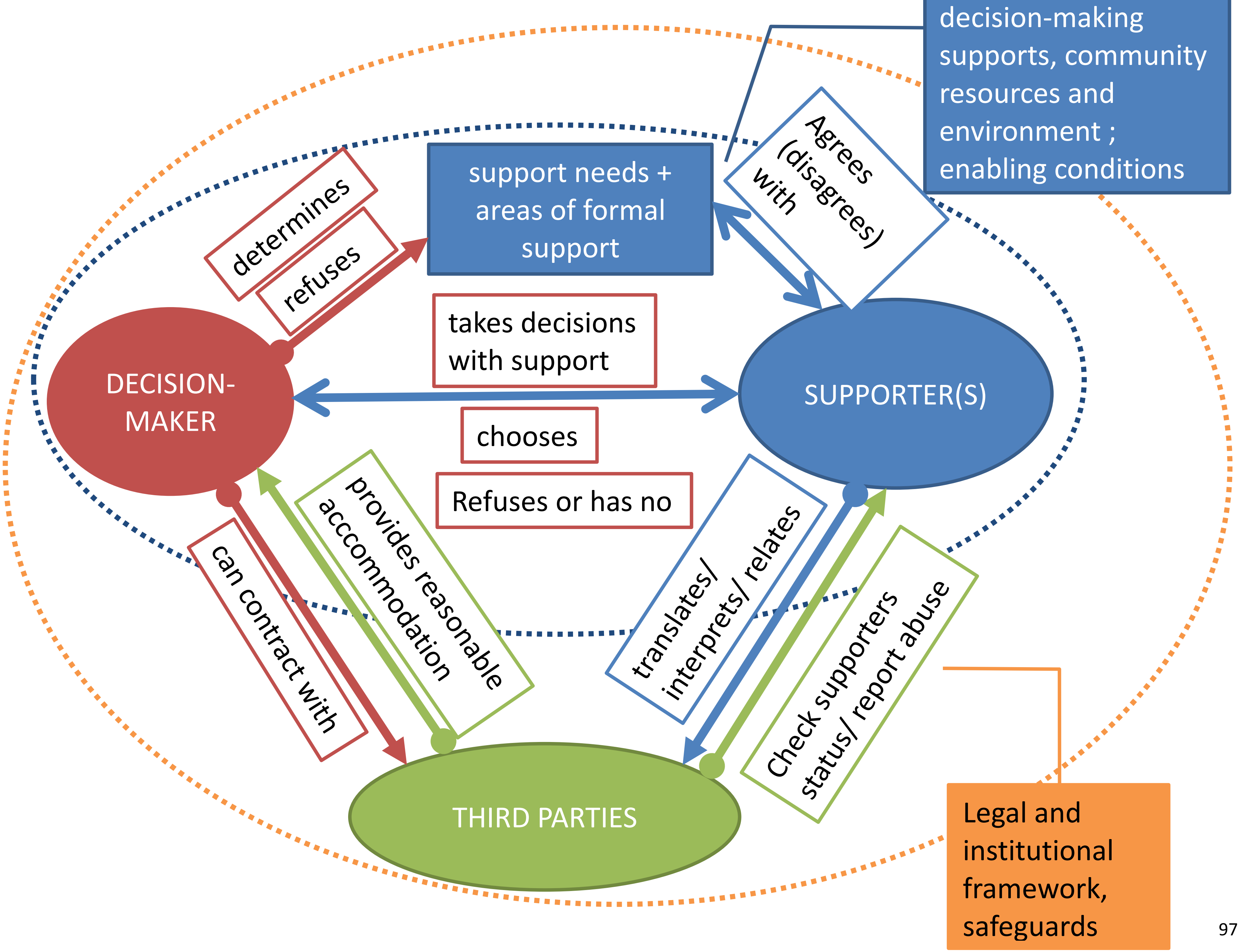
In her description of the change in paradigms from incapacity to capacity, Booth Glen defines the current "*emerging paradigm*" as embedded together with the notion of inclusion and the development of person-centred planning and self-directed services. Autonomy is preserved and people with disabilities remain legal actors, while the focus is on support to take decisions rather than on their legal status (Booth Glen, 2012). The new paradigm of legal capacity places the person and his/her support needs at the centre of the new model. It works with circles of support based on informal relationships and playing the role of informal safeguards (Gooding, 2017).

The following graph presents a person-centred schema of a supported decision-making model with micro, mezzo and macro levels.

The decision-maker, the supporter(s) and the third parties are the main actors in the decision-making process. The person's activities are described with verbs, which put the person at the centre of his/her support system and in control of it – this is why he/she is called the decision-maker. The supporters' role is twofold: supporting the decision-making and translating/interpreting/relating decisions to third parties. This is referred to as the *micro-level* or individual level, which determines supported decision-making arrangements tailored for individuals.

The term *mezzo level* refers to the: supported decision-making arrangements in interaction with third parties and the role of other actors from the community in the life of individuals. Third parties represented in green provide reasonable accommodation and can check the validity of the support and the decisions. All the elements related to the support environment and the community level are depicted in blue. The mezzo level is essential to the implementation and realisation of decisions – because this is the validation of decisions by others who are parties to the decisions. It is also important because the mezzo level corresponds to the environment and the circumstances in which people can take decisions and have access to different community resources. The mezzo level is therefore where opportunities to grow (Dhanda, 2007) are created and where people with support needs may move in an environment providing the "enabling conditions" (Flynn and Arstein-Kerslake, 2014a). The tools available for support in exercising legal capacity and accommodations allow individuals to move on a continuum of support, which is contingent and specific to each community.

And finally, the overall legal and institutional framework supports the system. The legal safeguards guarantee that there is an opportunity to challenge or modify the support arrangements (MDAC, 2013) by the person him/herself or by an external actor. This is the *macro level*. Most policy documents or academic papers address the macro level or the state-level, listing necessary steps to implement Article 12 such as 1) law reforms, and holistic examination of all areas of law, in order to abolish any restriction of legal capacity; 2) the introduction of supported decision making arrangements to replace substituted decision-making; 3) information/education campaigns and activities as well as 4) setting safeguards to prevent abuse (MDAC 2013, CRPD Committee, 2009).



decision-making supports, community resources and environment ; enabling conditions

determines

refuses

support needs + areas of formal support

Agrees (disagrees) with

takes decisions with support

DECISION-MAKER

SUPPORTER(S)

chooses

Refuses or has no

can contract with

provides reasonable acccommodation

translates/ interprets/ relates

Check supporters status/ report abuse

THIRD PARTIES

Legal and institutional framework, safeguards

The schema of course presents a simplified version of a rather complex issue, but it shows the model in a dynamic way. It also highlights the fact that the three levels overlap and captures the key elements of the framework for the pilot project analysis. While hard cases or difficult situations may not appear at first glance in this simplified schema, they are referred to under the terms "refuses" "refuses/has no" or "disagrees".

So, to set a system of supported decision-making, individuals benefit from a person-centred organisation of support (*micro level*) – embedded in a free and accessible system, where the decision-maker can make legally valid decisions, as his/her capacity is presumed and he/she is protected by a system of safeguards (*macro level*) – with recognition of this support by community members and institutions, who can react to the needs of the person – positively or negatively, for example in case of abuse (*mezzo level*). This gives the micro, mezzo and macro levels model as follow:

MICRO LEVEL	Individual support level: day-to-day informal support (by family, staff, friends, volunteers), communication/ facilitation/interpretation support, formal support or representation, life planning support, money management and other life skills training (autonomy and empowerment), informal safeguards by circles of supports
MEZZO LEVEL	Community level: formal recognition of supporters (register), interaction with third parties, reasonable accommodation by third parties, out-of-court dispute mechanism/mediation, peer support/self-advocacy or user's organisations, supporters organisations, social services available to people with disabilities
MACRO LEVEL	State level: neutral and non-discriminatory legal framework, institutional and judicial framework (including safeguards and access to justice), policy guidance, information and education campaigns, resources available to access support, duty of the state in providing reasonable accommodation (including contract law accommodation)

The three levels (micro, mezzo and macro) enable the various aspects relevant to the implementation of Article 12 to be taken into account. External factors, such as the social and political environment, and existing support services for people with disabilities, influence the supported decision-making system. However, this division into three levels of implementation helps to provide a holistic approach while not losing the central element that each person is entitled to take decisions with support.

Pilot projects have been conceived as "ideas-feeders" for law and policy reforms, for which the state is responsible. Out of the three levels of implementation, nine key elements to be looked at have been identified. The nine key elements of the framework thus provide a concrete tool to analyse the pilot project data and results in a way that can provide concrete recommendations for policy and law reforms as well as the practical implementation of Article 12.

The following section explains the reason for including each of the nine domains in the framework and what needs to be explored by pilot projects.

4.2 Nine domains to operationalise supported decision-making in pilot projects

The nine domains of the framework are presented in the following sections. The main issues at stake and a set of questions which will guide the analysis of pilot projects are described for each domain.

4.2.1 Domain 1: Being a person before the law

The first domain refers to the fundament of Article 12: who is a person before the law? Who can be a decision-maker? Who are the people who may need support in exercising their legal capacity? Being equal before the law may have a different meaning in different places. To have legal capacity recognised, a pre-requisite is that every human being is respected as a person possessing legal personality (CRPD Committee, 2014). The question of personhood, described in the narrative review, is extrinsically linked to the notion of autonomy. Several criteria of personhood have been discussed by scholars. Michael Bach defines a person before the law as "*people who can express their intention or 'happiness' at choosing one course of action over another*" (Bach, 2009). The behaviour of a person that can express will and communicate intention can be used as the main criteria of personhood. The intention is also the basis of a person's capacity to enter a contract, from a contract law perspective. Criteria of personhood can include the story of one's life, which can be related by others who know the individual well. Pilot projects may have taken a different approach to personhood. The criteria that pilot projects have put in place to determine who can be a decision-maker, on the basis that people with disabilities are persons on an equal basis with others (Article 12(1)) will illustrate their understanding of the notion of personhood. Pilot projects ambition to test a model that universally applies to all people who may need support in exercise legal capacity.

Set of questions related to being a person before the law:

- How did the pilot projects conceptualise equality before the law?

- How did the pilot projects understand personhood and which criteria did pilot projects use to define personhood for people with cognitive disabilities?

4.2.2 Domain 2: Determination of support needs

The second element looked at is what support the individual needs, mainly how support needs are determined. This is a crucial element as support needs assessments should not be based on a diagnosis but should use disability neutral criteria, as discussed in Chapter 2. Scholars have extensively described several models which are not disability-neutral and why new neutral criteria need to be developed (Flynn, Arstein-Kerslake, 2014a, 2014b). Other scholars have suggested a mix of different elements, including the presence of a disability, as in the notion of decision-making capabilities (Bach and Kerzner, 2010). In addition, support needs should be determined for each specific person but the scope of the assessment should only aim to identify the support that the person requires to exercise legal capacity (Gooding, 2013) and not expand unnecessarily. What models and tools for determination of support needs have been used by pilot projects is a key question, as well as the justification for using them.

Another question is how the individual is involved in the choice of support level he/she requires. Each individual should have a say in determining their support needs, as his/her will and preferences should be respected. The identification of support needs should also determine whether formal support should be provided. There are people who do not need legally appointed supporters – informal support suffices. It is also important to avoid some form of "over legalisation" and to maintain and protect the informal decision-making or day-to-day decisions (Bach, 2009). Pilot projects may set criteria and tools to determine support needs, and consequently in which areas formal (and informal) support is needed.

This element of the framework covers the issue on how to deal with people who refuse support, as this right to refuse is recognised by the CRPD (CRPD Committee, 2014; Flynn and Arstein-Kerslake, 2014a). The right to refuse support relates to a risk of harm. What level of risk of harm is acceptable without interfering with the right to support? Should a proportionality test be applied as for other human rights inference?

Pilot projects may encounter people who refuse support; therefore, it would be interesting to consider how the pilot projects responded to such cases and what can be learned from the project's response.

The following questions are relevant to how a person’s support needs are determined:

- How did the pilot projects determine the person’s support needs? What criteria were used to determine support needs and were those disability-neutral criteria?
- What tools and methods did the pilot projects use to assess support needs?
- Who conducted the assessment? How did the pilot projects involve the person in the choice of support level he/she requires?
- Did the pilot projects combine formal and informal decision-making assistance and if, so, how? How did they assess the need for formal decision-making?
- If the pilot projects encountered people who refused support, what was their response?

4.2.3 Domain 3: Available support

The third key element is the type of supports for decision-making that are offered. The CRPD Committee in its General Comment No. 1 defines support as “*a broad term that encompasses both informal and formal support arrangements, of varying types and intensity*” (CRPD, 2014). A wide range of options to support people to exercise their legal capacity and the process with their decision-making have been listed and described by scholars: advance or life planning, independent communication and interpretative supports, relationship-building supports, administrative supports (Bach and Kerzner, 2010), trusted persons, peer support, independent advocacy, self-advocacy (CRPD Committee, 2014), mainstream consumer’s mechanism, (Inclusion Europe, 2009) or representative support (e.g.: the Representation Agreement of British Columbia or the Irish Assisted Decision-Making Act) (Gooding, 2017). This list is not exhaustive as the concept of supports for decision-making in an evolving concept (Gooding, 2013). New programmes and methods could also enlarge the scope of support as it is currently understood (Minkowitz, 2007). The key question is what kind of support arrangements pilot projects used and how they interpreted the requirement to respect people’s will and preferences.

The pilot projects also looked at different areas of life where support can be provided (financial affairs, housing, health care, personal life decisions: work, leisure-time activities, relationships, etc.) and may have selected specific support arrangement for certain areas of life. One area where Article 12 raises hugely legal complex issues is the area of contact law. Persons with intellectual and psycho-social disabilities regularly face discrimination, abuse and denial of legal capacity in seeking to enter, exit, modify or enforce contracts. A detailed legal analysis of how these issues are to be resolved is beyond the scope of this research. Two issues should be briefly mentioned here. One aspect is the fact that pilot projects may set a specific lower threshold to enter into an agreement of supported decision-making than for other types of contracts and agreements. Another issue is the available support for the exercise of the legal capacity to contract on an equal basis with others in an effective way – there is space for innovation, and new accommodation practices (Wayne, 2018). Pilot projects may have looked at some possible accommodations.

The following questions relate to what supports are offered and available to people:

- What support for decision-making was made available/offered by the pilot project?
- What tools and measures (if any) did the pilot projects use? How did the pilot projects select them to ensure that the person's will and preferences and human rights were respected?
- How projects have conceptualised and used a panel or circle of support to support people in exercising their legal capacity?
- What support is offered in relation to decisions concerning financial affairs? housing? health care? voting? entering a contract? Or in relation to personal decisions (work, relationships, leisure time activities and holidays?)
- How pilot projects have envisaged freedom of contract for people with cognitive disabilities? What accommodations to the capacity to contract did the pilot projects use?

4.2.4 Domain 4: Supporters: duties and responsibilities

For most people with intellectual and psychosocial disabilities support in decision-making will be provided by trusted people both via informal day-to-day assistance, including assistance in communication and/or as a formally recognised supporter or representative.

Pilot projects may rely on existing networks to choose supporters from or involve new people, as we have seen in the previous chapter. It is crucial that people with disabilities should be able to choose who they want to support them, wherever there are family members, friends or other independent advocates. Pilot projects have worked on determining trusted relationships and creating support networks and they also have trained supporters. The key question is who is supporting (what is the relationship with the decision-maker) and what duties do supporters have when they act as formal assistants.

This domain however also looks at how to create support networks for people who have no trusted relationships, for example people who have been institutionalised for a long period or people who have been/are very isolated. Pilot projects have to deal with people who have no natural support (family, friends and other acquaintances) and may involve paid staff or supporters (support from social services staff, public guardians, who perform these tasks as part of their job) or volunteers. Training content for and duties of supporters may be different when supporters are from the family/friends circle and when they are volunteers or paid supporters.

The question of duties also brings up the issue of the liability of supporters. There is a need to protect the support person who helps to make a decision or interprets the person’s wishes and intent, as they are acting on the basis of a trusted relationship, not as an expert. Supporters need to know when and for what they will be legally responsible. Michael Bach has proposed that supporters should not be held liable if they have complied with their duty of care and have not acted negligently (Bach, 2009). Pilot projects need to conceptualise liability for different groups of supporters and make it work in practice so that supporters know about their duties and responsibilities.

The following questions related to the duties and liability of supporters:

- What methods or techniques were used to create support networks? How have potential new supporters been reached out to and involved in the life of individuals with disabilities?
- What means have been used to explain their duties to supporters? Guidelines / practice guidance? Did the pilot projects create different material for family members and friends and other groups of people?
- What guidelines have been developed and tested to protect supporters from liability?

4.2.5 Domain 5: Supported decision-making processes

A critical element is the process of supported decision-making. The General Comment on Article 12 sets that decisions have to be taken according to the rights, will and preferences of the person (CRPD, 2014). At the same time, many scholars have noted that this is an area where there is a lack of information: there is no evidence based on the process of supported decision-making (Kohn and Blumenthal, 2014; Kohn et al., 2013). As described in Chapter 3, pilot projects have attempted to record supported decisions but this was not carried out systematically in all projects and sometimes only the outcomes of the decisions have been recorded and not the processes. Pilot projects should use mechanisms to record decisions and monitor them to ensure that they are the decision-maker's decisions and not the supporters' ones. Secondly, taking a decision is one step, but the second step is to engage and make agreements, to act on the decision which has been made. This is also an important part of the supported decision-making process, ensuring the concrete realisation of decisions.

The more difficult situations are where the person's will and preferences are unclear, conflicting or absent. The CRPD Committee has set the notion of "*best interpretation of will and preferences,*" which replaces the former "best interests" determination. This can be explained as follows: "*the representatives will have to take decisions in a way which attempts to draw out the imagined will and preferences of the person*" (Flynn and Arstein-Kerslake, 2014a). Pilot projects will have to translate this principle in practice, through practice guidance which should specifically frame support decision-making processes in situations where the will or preferences are unclear or absent. Pilot projects will have to develop guidance which explains the difference between best interests and best interpretation of will and preferences. Similarly, guidance on how to respond to situations of emergency (imminent risk or serious adverse effect) is required.

Another key aspect which goes with the process of support in decision-making is what is defined as "*the dignity of risk*" (Bach, 2009; Gooding, 2013), as the matter of risk taking is a crucial component of decision-making. Risk taking is a "growing" concept: while the capacity of the individual evolves and experience is gathered, risk taking can become more important. Therefore, in practice risk assessment tools should be used to empower people to take decisions and learn from them. Pilot projects should have guidance to work with risk situations. In relation to risk taking, there is a debate on the question as to whether the provision for nullification of a contract should be preserved under a CRPD-compliant regime of contract law or not. The question is whether it is a meaningful protection/safeguard for persons with disabilities when it requires a legal or administrative procedure to nullify the contract.

The following questions relate to how support is provided:

- Which mechanisms did pilot projects create to ensure that decisions are made with respect to the rights, the will and preferences of the person (practice guidance, guidelines, facilitation of decision-processes)?
- What monitoring mechanisms have been put in place to evaluate the decision-making process and its outcome?
- How have decisions been recorded? What guidelines have been developed to building a history and a track record of supported decisions?

- How did pilot projects seek to clarify the difference between best interest decisions and best interpretation of the will and preferences?
- If pilot projects are confronted with situations where the will or preferences are unclear or absent, what guidelines have been developed and tested to support the decision-making processes?
- Have pilot projects been confronted with emergency situations or situations of serious adverse effect? How did they respond?
- How were risks assessed in the pilot project? Has a risk assessment plan been tested in the framework of the pilot projects?

4.2.6 Domain 6: Interactions with third parties

People with disabilities and their supporters will need recognition by third parties of their support relationship, so that supported decisions will be accepted by them. Some solutions already exist –. For example, this relationship could be verified by an official document or a card, issued by an authority, court, ministry or a resource centre, which would be given capacity for this. Or a registration system can be created, and then the question is if it should be a public registry or if the access to it should be restricted – should private entities like banks or doctors then have access to it or not? Beyond the technical question and the issue of personal data protection, pilot projects participants may be confronted with third parties' reluctance to accept their supported decision. Third parties also have a positive role in preventing any situation of abuse and should report potential abuse. Third parties should respect support arrangements but they should also proactively provide reasonable accommodation, as a duty towards their clients or patients with disabilities.

The following questions relate to the interactions with third parties:

- What system has been conceptualised by pilot projects to verify who is a support person?
- What experience can be reported from the pilot projects regarding interaction with third parties?
    - How did third parties accept or challenge the role of supporters of pilot participants?
    - Did third parties offer decision-making supports or provide accommodation based on supporters or others' suggestions?

4.2.7 Domain 7: Reasonable accommodation

Reasonable accommodation applies to Article 12 as all other articles of the CRPD. As noted in Chapter 2, the right to reasonable accommodation in the exercise of legal capacity is separate from, and complementary to, the right to legal capacity (CRPD Committee, 2014). The right to reasonable accommodation relates in this context especially to the provision of accessible information regarding decisions which have legal effect, access to courts, banks, social benefit offices and polling stations. The duty to provide reasonable accommodation is shared between the state and third parties, when Article 12(3) and Article 5(3) CRPD are read in conjunction (Bach and Kerzner, 2010). Beyond third parties, the state has the obligation, under Article 9 CRPD, to ensure the equal enjoyment of goods and services in the private sector and to provide information in accessible formats (CRPD Committee, 2018).The duty of accessibility should be used for people with disabilities to access information and services related to the exercise of their legal capacity. Reasonable accommodation can be requested by an individual or by a group of individuals, when he/she or they want to exercise their right. Therefore, the duty to provide for reasonable accommodation applied in practice during the realisation pilot projects, regardless of legal framework on legal capacity. The only limitation is that it should not create a disproportionate or undue burden on the accommodating party, or as the CRPD Committee interpreted in a narrower way: an "*excessive or unjustifiable*" burden (CRPD Committee, 2018).

Some authors also explore the idea of a Universal Vulnerability Approach to contracts. The notion of "vulnerable customers" for whom specific duties and services (and specific costs!) could be provided, would simply reinforce discrimination and paternalistic interventions in the life of people with disabilities. But if all the parties are considered as vulnerable beings, institutional preconditions that enable functioning in the market via contract could be sought (Wayne, 2018). One aspect that pilot projects may look at and review contract rules to set new practices based on a universal vulnerability approach compliant with the CRPD in this domain.

Set of questions related to the provision of reasonable accommodation:

- How have the pilot projects worked with the notion of reasonable accommodation in the exercise of legal capacity for individuals or groups of individuals? Have they initiated reasonable accommodation with specific third parties?
- Could the pilot projects participants suggest reasonable accommodation? Was it accepted? Was it denied?
- Have pilot projects explored possible accommodations or special measures to include vulnerability in contracts?

4.2.8 Domain 8: Safeguards

Safeguards are an essential element of a supported decision-making regime. While some key safeguards cannot be put in place during the realisation of pilot projects, because they need to be enshrined in law, several safeguards can be organised within a pilot with a view to being formalised then as part of the institutional and judicial system at a later stage. Safeguards include formal safeguards, such as those listed in Article 12(4) CRPD as well as informal safeguards. Informal safeguards may include relationships with family, friends, personal networks, neighbours and members of the wider community (Gooding, 2017). Therefore, different mechanisms of informal safeguards may be tested within the pilot projects.

First of all, **advice and support** should be available to people with disabilities and their supporters, as well as to third parties to get answers to any of their questions or doubts about their role that may arise in the supported decision-making relationship. This function can be organised within the pilot project and could be run in the future by a resource centre, which may also explain supported decision-making, train supporters and facilitate supported decision-making arrangements (Inclusion Europe, 2018).

Another key safeguard is an **accessible dispute resolution mechanism**. It is often difficult for people with intellectual disabilities to solve a conflict on their own or to challenge their supported decision arrangements or decisions. They need sufficient support from their surroundings. Without this they are unlikely to be successful in pursuing their complaint. Therefore, they need either someone specific to support them in the dispute or a third person to help resolve both sides. It may be an informal person, for example a common acquaintance, or it may be a dispute resolution professional (e.g.: a mediator who had special training to work with people with cognitive disabilities). Only as a matter of last resort should legal proceedings be needed. Again, pilot projects may provide for an informal accessible dispute resolution mechanism.

Another key safeguard is the **monitoring of supporters**. The issue of monitoring and supervision is a complex and a large one, which needs flexible institutional mechanisms in place. However, pilot projects may touch upon issues related to who should monitor and who should be supervised. Indeed, an important question is whether it will do more harm than good to monitor supporters from the family and friends circles. Some sort of monitoring may be needed but it will be important to avoid unnecessary interference in people’s private lives. The second question is who should do this check? Out-of-court mechanisms should be preferred. A first level of monitoring could be done at municipal/local level, by a resource centre, or by non-profit organisations, mainly undertaken by social workers. What should be monitored and how? Property and money management are usually under supervision, as there is a concern of financial abuse. Instruments for general monitoring looking at how rights, will and preferences of the person are respected and followed by supporters in the decision-making processes should be explored. Specific guidance will be needed for monitoring in cases of best interpretation of will and preferences.

One potential *ex-ante* supervising mechanism is the figure of the Monitor, as it works in the British Columbian model. The Monitor oversees the work of the formal supporter(s) and for important decisions it can require documents to make sure that the rights and the preferences of the person have been respected and followed (Bach and Kerzner, 2010). Monitors could be appointed permanently or for important decisions only, based on the concrete decision to be taken.

Finally, **regular reviews** of decision-making measures should be in place. Revision of support should be done on a regular basis with the participation of the person concerned. It is important, however, to avoid a high administrative burden – the revision of support arrangements should be effective and supportive of the autonomy of the individual and not be degrading for the person (for example by requiring a medical assessment or other stressful assessment). Again, out-of-court regular reviews would be more accessible for decision-makers and supporters and could help in preventing disputes. Regular reviews should look at how support is provided, discuss if the amount of support is adequate and, eventually, amend or remove support. These regular reviews need to take place with sufficient frequency (Inclusion Europe, 2018).

The following questions relate to safeguards and protection against abuse:

- How did pilot projects consider and conceptualise informal and formal safeguards?
- What did pilot projects plan to advise and support decision-makers, supporters and third parties in case of doubts about their rights and duties?
- What role did facilitators play in safeguarding?
- What mechanism did the pilot projects propose in cases of conflict between the decision-maker and the supporter? Who should support a person with disability in a conflict, in order to guarantee his/her fair participation?
- How was monitoring conceptualised and planned in the pilot project?
    - Who should monitor supporters? And what should be monitored (avoiding administrative burden in the life of people with disabilities and their network members)?
    - How frequently should review of support arrangements take place? Who should facilitate this review?
    - What out-of-court mechanism(s) can be used?

4.2.9 Domain 9: The cost of the support

The last element of the framework relates to the costs of the support. For policy and law reforms it is of outmost importance to evaluate the costs of the support, not only in financial terms but in also in terms of time/person involvement as well as in terms of benefits from a societal point of view. The evaluation reports discussed in Chapter 3 raised the question of the huge staff involvement necessary to work with pilot project participants. In addition, the General Comment states clearly that to comply with Article 12, "*States parties must ensure that support is available at nominal or no cost to persons with disabilities*" (CRPD Committee, 2014). While it is probably unlikely to track the amount of time spent by a support network for day-to-day support (and it may overlap with daily care issues), it would be relevant to measure the time a network is involved in specific decisions (length of the process, numbers of meeting around the decisions, external visits or activities to build knowledge around the decision, discussion time, etc.). Secondly, it would be interesting to measure the time invested in building new networks for isolated people and to create track records of decisions when facilitators or independent advocates are involved. It is important to have some benchmarks both for people who have support and for those who have insufficient or no support at all, in order to equip the community with sufficient resources. The state indeed has an "*absolute obligation to provide access to support in the exercise of legal capacity*" (CRPD Committee, 2014) – that implies there should be ways to access resources, both by state direct support or through funding schemes or funded resource centres or DPOs/NGOs established for this role.

The element related to the cost of support should be reflected in the pilot projects policy and advocacy documents and recommendations for policy and legal reforms.

The following questions relate to the costs of support:

- Have the pilot projects analysed what resources are needed for formal decision-making with support (the work involved by how many people and how much time)?
- Have the pilot projects analysed what resources are needed to achieve decisions made on the best interpretation of the will and preferences of individuals who have no experience or history of decisions?
- Have pilot projects analysed what resources are needed to create a support network for people who have no relations and are socially isolated?
- What benchmarks have been set to evaluate the quality of life with the supports provided in the exercise of legal capacity to pilot project participants?

In total, the proposed framework contains nine domains to explore for the analysis of pilot projects. The areas and the related questions are not exclusive and are meant to be enriched further in this research and beyond. Questions have been used to serve this purpose and ensure that the framework is a dynamic instrument. While it will structure the analysis of the pilot projects, there is room for other things to emerge, either within the key elements or even as a new element.

In Annex No. 2, a table version of the framework also proposes potential measures to be tested or indicators as possible ways to answer to the questions the framework addresses. The indicators are suggestions based on the kind of pilot project record, documentation and material that may be available and that can be potentially developed within a pilot project.

The framework with its set of questions to explore each domain and the indicators to look at will guide us in the analysis of the pilot projects to find answers or partial answers to the questions and the problems addressed by those pilots. The answers may not be definitive or comprehensive ones, but each element can contribute to advancing the practical implementation of Article 12 and provide further clarification to the concepts of supported decision-making and universal legal capacity.

The following chapters provide a description of the methods (Chapter 5), an initial mapping of each pilot project included in the research (Chapter 6), an analysis of the pilot projects documentation and interviews for each domain of the framework (Chapter 7) and a description of other topics which emerged from the pilot projects (Chapter 8).

5 Methods

The study of pilot projects aimed to provide clarification about the concepts of Article 12 and about ways to implement Article 12 in practice.

In particular, it sought to answer the following questions:

- what criteria and characteristics should models of support fulfil to be compatible with Article 12?
- what lessons have we learnt from the pilot projects?
- how pilot project outcomes contribute to the advancement of implementation of Article 12?

To answer these questions, this research explored first of all evaluated pilot projects, as described in Chapter 3. However, as demonstrated, the intrinsic limitations of these projects and the limitations of the evaluations did not provide sufficient elements to answer the research questions above. But it confirmed the need for systematic data collection about the characteristics, the implementation process and the outcomes of pilot projects. It also highlighted the need to look both at processes from the individual perspective and from the system perspective. Chapter 4 proposed a framework with its set of questions to guide the analysis of pilot projects. This chapter gives a detailed overview of the methods of data collection and data analysis with the questions of the nine domains of the framework.

5.1 Data collection

5.1.1 Pilot projects selection

Seventeen countries implementing pilot projects[64] were identified and listed by the researcher during several conferences, workshops and international exchange meetings on legal capacity. Evaluated projects which had been already looked at in Chapter 3 were excluded from the list. Then, pilot projects working only on legal reforms (e.g. advocacy and legislative work around reform or recodification of the Civil Code) were excluded from this list. Finally, pilot projects for which no information was available in a language that the researcher could read (English, French, Czech and Spanish languages) were also excluded. The study thus included only pilot projects realising field work with participants with intellectual and/or psychosocial disabilities, according to the researcher's knowledge.

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[64] This number of pilot projects refers to a screening made in the years 2016-2017. It includes: Argentina, Australia, Bulgaria, Canada, Colombia, Czech Republic, Georgia, China, India, Ireland, Israel, Kenya, Latvia, Lithuania, Mexico, Peru and the United States.

The pilot projects were therefore selected on the basis of two criteria: first, the realisation of field work with persons with disabilities and secondly, contacts available to the persons in charge of the project[65]. The researcher contacted pilot projects coordinators and staff by email with the necessary information regarding the research and information about the approval by the Tizard Ethics Committee. In total, eight organisations were contacted, of which two did not reply[66]. Eventually, six pilot projects were the focus of this study.

5.1.2 Measures

To collect data about the pilot projects, individual interview was selected as the most appropriate instrument to work across different language and different time zones. It also ensured that enough time would be spent to understand different aspects of the projects. A preliminary survey to collect quantitative data was designed as a separate instrument to allow interviewees to find the information in their files, outside the interview time. The third source of information about the pilot projects was material and publications written during the pilot or as outcome of the pilot. The researcher asked pilot project staff to share existing material but also searched on her own all existing material and publications. Only one of the pilot projects had a dedicated project website (New - York), while the others had some information on the organisation's website.

Thus, to collect data about the pilot projects two instruments were created:

1) a preliminary survey including questions about the project participants, their demographic and personal characteristics as well as basic information about the pilot project (Annex No. 3). Chapter 3 showed the importance of collating data about the pilot projects participants for the validation of the implementation of Article 12. The evaluation reports did not provide evidence of the participation of people with more profound disabilities. It also showed that fewer projects worked with people with psychosocial disabilities.
2) a semi-structured questionnaire to guide interviews with key informants (Annex No. 4). The questionnaire included open questions about the project and the different phases of implementation: recruitment phase, realisation phase, outcomes and the next steps.

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[65] Many projects had no website with actual contacts, or the contact person changed.

[66] Latvia and Peru (the organisation responsible for second pilot project in Peru – the other pilot project being part of this study) .

5.1.3 Data collection

The pilot project coordinator or contact person was asked to complete the preliminary survey form and send it back to the researcher, together with the consent form, before the interview took place. All the informants sent the survey form back. However, they did not necessary collect all the characteristics of the participants listed in the survey. Detailed data about the pilot projects participants are presented in Chapter 6 and an overview of basic pilot projects features is available in Annex No. 5.

Interviews took place from June to October 2018, with either one or two interviewees as was the case for Colombia and Zambia. The interviewees were all pilot project staff – in the case of Zambia one of the informants was a person with psychosocial disability working for the pilot project. Interviews typically took about one and a half hours. Interviews took place online via Skype or in person and were recorded with a dictaphone or an online recorder software. The transcriptions of the interviews was then made by the researcher and typed in a Word document. The interviews were then proof-read and in places where the interview record was not understandable, it was marked as such. An extract of the interview with the Director of the Peruvian Down Syndrome Society is available in Annex No. 6.

Data collection also included material developed by the pilot projects. It comprises different types of documents: policy document, draft law, practice guidance, evaluation report, project report, academic article, as well as different project material (presentation, online course, material for pilot projects participants, as well as videos or leaflets).

A follow-up email was sent in the weeks or months following the interviews, as in most cases some additional material was in preparation at the moment the interview took place. With the exception of Zambia because of staff turnover in the organisation leading the project, the informants sent additional material developed by the pilot projects. Material produced in 2019 and 2020 and made available to the researcher was included in the data collection for this study.

In the case of the pilot projects in Peru and New-York an external evaluation report was produced later in the course of this work, after completion of the chapter on evaluated pilot projects. The evaluation report of the New York project was not a post-project report, but focused only on the first two years of the project and therefore it was not a comprehensive evaluation of the project. The report of the Peruvian pilot project was a post-project report but did not include policy and legal aspects. Both reports were not comprehensive but they included useful information about the project (and allowed fact checking of the data recorded by the researcher during the interviews) but mainly they reported quotations from pilot projects participants (people with disabilities and supporters, as well as staff) – therefore this was a substantial source of valuable input for this research. This is why it was decided to include these evaluation reports as one source of information along with other pilot project documents. The researcher gathered more detail and information about the project. The reports did not primarily aim to analyse the project in relation to Article 12, therefore they did not interfere in the analysis through the questions of the framework. As already noted in Chapter 3, the evaluation reports did not critically look at the implementation of Article 12.

To sum-up, for each pilot project, the data available included:

- the preliminary survey with information about the pilot project participants (reported in Chapter 6 – in the sections key facts and project participants)
- the transcript of the interview with key informant(s) about the different phases of the pilot projects and further activities (reported in Chapter 7 after being analysed through the questions of the framework)
- project material with different content and of different length (also reported in Chapter 7 after being analysed through the questions of the framework)

Each source used in this research is described in the presentation of each pilot project in Chapter 6.

An overview of all the sources analysed in chapter 7 is provided below:

CODE	**Nature of the source**	**Name of the source**	**Authors**	**Year**	**Language**
PE_INT_1	Interview with project staff	Interview with Liliana Peñaherrera Sanchez, Director of the Peruvian Down Syndrome Society		2018	English
PE_DOC_1	External evaluation report	Proyecto “Ejerciendo Ciudadanía” Informe Final de Evaluación Externa *(“Exercising Citizenship" Project Final External Evaluation Report)*	Francisco Diez Canseco Montero	2018	Spanish
BG_INT_1	Interview with project staff	Interview with Nadia Shabbani, Director of the Bulgarian Center for Not-for-Profit Law (BCNL)		2018	English
BG_DOC_1	Practice guidance (including template)	Guidebook to rights enforcement	BCNL	2014	English
BG_DOC_2	Policy document (legal aspects)	New „formula“ for capacity to act - opportunity for everyone to exercise their rights Statement on the paradigm shift of Article 12 of CRPD	BCNL	2014	English
BG_DOC_3	Policy document (economic aspects)	Cost Benefit Analysis of Supported Decision-Making	BCNL	2014	English
BG_DOC_4	Legal analysis	Sufficiency of law, Deficiency of rights The Legal Capacity to Act as a Universal Standard of Being Human The International Perspectives and the Bulgarian Legal Reform	BCNL	2015	English

BG_DOC_5	Draft law	Natural Persons and Support Measures Act		last version 3.3.2015	English
BG_DOC_6	Policy document (legal and policy aspects)	Challenging the law and policy framework for people with intellectual disabilities and mental health problems to exercise their rights what, where and how guidelines for policy changes	BCNL	2014	English
BG_DOC_7	Legal analysis	Incapacity to Act of Natural Persons. Contemporary Challenges	Stoyan Stavru	2016	English
CO_INT_1	Interview with project staff	Interview with Monica Cortes and Consuelo Pachon, Asdown Colombia		2018	Spanish
CO_DOC_1	Project report to donor	Informe narrativo 1 *Narrative report 1*	Asdown Colombia	2015	Spanish
CO_DOC_2	Project report to donor	Informe narrativo 2 *Narrative report 2*	Asdown Colombia	2015	Spanish
CO_DOC_3	Project report to donor	Informe narrativo 3 *Narrative report 3*	Asdown Colombia	2016	Spanish
CO_DOC_4	Project report to donor	Informe narrativo 4 *Narrative report 4*	Asdown Colombia	2016	Spanish

CO_DOC_5	Project material: Online training course	Curso - Systemas de apoyo para la toma de decisiones para las personas con discapacidad Guía Técnica del Curso de Formación Virtual *Course - supported decision-making systems for people with disabilities* *Virtual Training Course Technical Guide*	Asdown Colombia Nodo Comunitario de Salud Mental PAIIS	2017	Spanish
CO_DOC_6	Project material: Online training course	Curso virtual (modulo 2) *E-learning (module 2)*	Asdown Colombia Nodo Comunitario de Salud Mental PAIIS		Spanish
CO_DOC_7	Policy document (including legal analysis and templates)	El ejercicio de la capacidad jurídica: Guía práctica para su aplicación *The exercise of legal capacity:* *A practical guide to its application*	Asdown Colombia Nodo Comunitario de Salud Mental PAIIS	2019	Spanish
CO_DOC_8	Academic article	De la exclusión al reconocimiento de la capacidad jurídica de las personas con discapacidad intelectual y psicosocial en Colombia: hacia la construcción de sistemas individuales de apoyos *From exclusion to recognition of the legal capacity of persons with intellectual and psychosocial*	Consuelo Pachón Suárez, Ana María Barragán Díaz, Catalina Correa, Felipe Gartner Jaramillo, Yenny Guzmán y Paula Torres		Spanish

		disabilities in Colombia: towards the construction of individual support systems.			
CO_DOC_9	Law	Ley 1996 de Agosto 2019 por medio de la cual se establece el régimen para el ejercicio de la capacidad legal de las personas con discapacidad mayores de edad *Law 1996 of August 2019 establishing the regime for the exercise of the legal capacity of persons of legal age with disabilities.*		2019	Spanish
CZ_INT_1	Interview	Interview with Dana Kořínková, project leader and lawyer, Quip		2019	Czech
CZ_DOC_1	Legal analysis	Černá kniha Odvrácená strana omezování svéprávnosti *The Black Book* *The flip side of incapacitation*	QUIP_SPMP	2015	Czech
CZ_DOC_2	Policy document (pamphlet for reforms)	Bílá Kniha *White Book*	QUIP_SPMP		Czech

CZ_DOC_3	Practice guidance (including instruments for individual work)	Podpora při rozhodování a právním jednání místo omezování svéprávnosti (metodika) *Support for decision-making and legal action instead of limiting legal capacity (methodology)*	QUIP_SPMP	2016	Czech
CZ_DOC_4	Evaluation of the experiences of participants in using decision-making instruments	Zkušenosti s nově nastavenou právní ochranou v oblasti podpory při rozhodování *Experience with the new legal protection in the area of Supported decision-makingt*	QUIP_SPMP	2020	Czech
CZ_DOC_5	Policy document (Legal aspects)	Legal Cases of Legal Capacity Restoration and the Use of Support in Decision Making	QUIP	2017	English
CZ_DOC_6	Project material: sample legal document (supported-decision agreement)	Agreement on SDM - example (anonymous copy)	QUIP		Czech
CZ_DOC_7	Policy document (legal and procedural aspects)	Záruky bezpečí *Safeguards*	QUIP_SPMP	2019	Czech
CZ_DOC_8	Practice guidance (for supporters)	Etické a metodologické principy poskytování podpory při rozhodování a právním jednání *Ethical and methodological principles for the provision of support in decision-making and legal action*	QUIP_SPMP	2017	Czech

CZ_DOC_9	Project material: sample legal document (trust fond contract)	Example of trust fund contract	SPMP		Czech
CZ_DOC_10	Project material: sample legal document (three-party agreement with bank, client, and supporter(s))	Dohoda o specifických podmínkách smluvního vztahu mezi bankou a klientem se zdravotním postižením *Agreement on specific terms and conditions of the contractual relationship between the bank and the disabled customer*	SPMP	2019	Czech
CZ_DOC_11	Project material: Easy read information material about banking	Easy Read materials prepared for banks	SPMP	2019	Czech
ZA_INT_1	Interview with project staff	Interview with Patience Kanguma, Zambia Federation of Disability Organisations (ZAFOD) and Sylvester Katontoka, Executive Director at Mental Health Users Network Of Zambia		2018	English
NY_INT_1	Interview with project staff	Interview with Matthew Smiths, project coordinator, SDMNY		2018	English
NY_DOC_1	Evaluation report by external evaluator	Evaluation report	Elisabeth Pell		English

NY_DOC_2	Academic article	Article "Introducing a "new" human right: learning from others, bringing legal capacity home" Colombia Human Rights Review,	Kristin Booth Glen	2018	English
NY_DOC_3	Academic article	Article " Supported Decision-Making From Theory To Practice: Further Reflections On An Intentional Pilot Project" Albany Gvt Law review	Kristin Booth Glen	2020	English
NY_DOC_4	Practice guidance (template)	Big Four Chart	SDMNY		English
NY_DOC_5	Practice guidance (template)	Material for facilitators (facilitation protocol, cheat sheet and worksheet)	SDMNY		English
NY_DOC_6	Project material: Presentation	Presentations about Supported Decision-Making New York	SDMNY		English

Table No. 2: Overview of all the sources used for the analysis of pilot projects and their codes

5.2 Extraction and analysis of data for the framework

The pilot project interviews and documentation (reports and legal analysis, policy documents as well as practice guidance) were analysed through the nine domains of the framework in the following sequence.

5.2.1 Data Extraction

A template for reporting in an excel spread sheet was created, mirroring the structure with the nine domains of the framework, with a separate spread sheet for each pilot project. In each spread sheet, two sets of columns for data from the interviews and data from the documentation were created to report the information from both sources with the exact page reference for each answer. All the questions of the nine domains of the framework were included for all the pilot projects. A final open section was created to add any additional points of interest.

First, data from the interview were coded with colour marks during a third reading of the transcripts, looking for answers to the framework questions. Where relevant data for a question of the framework was found, it was recorded in the spread sheet. The same process was applied and repeated with each project document one by one: highlighting with colour marks and notes while reading and identifying elements to answer the questions of the framework. All the questions of the nine domains of the framework were scanned in a systematic way. The relevant answers were then reported in the table, either as a summary of the data available in the material and the page references or by copying the relevant paragraph(s) of a specific document. Relevant quotes to be used at a later stage in the research were also included as an element of the answers. The answers were systematically translated into English from the original document by the researcher to include only data in English in the spread sheets. Only direct quotes were reported in both the original language and English to be able to improve the translation at a later stage.

In most cases, a last reading of the interview was carried out, as documentation could cast new light on the project and some aspects of the interview could be understood in a different way. This last reading of the interview also allowed the researcher to check that the content of the interview was well interpreted.

The data available from the project documentation and the interviews were incomplete and the amount of available data from the projects differed. The framework includes nine domains, each divided into two to eight questions, including sub-questions. In three domains only, data could be identified in all the pilot projects documents. Those domains are: 1) available supports for decision-making, 2) supporters' role: duties and liabilities and 3) supported decision-making processes. In the domains of determination of support needs, reasonable accommodation, and safeguards, some data could be found in most projects. The remaining domains – being a person before the law, interactions with third parties, and the costs of support data – could be found in only two to four projects. The Bulgarian project provided most answers to the framework (only three questions remained unanswered) while for the Czech, Colombian and New York projects about eight or nine questions remained unanswered. In the case of Peru and Zambia, more than half of the questions remained unanswered.

5.2.2 Data analysis

Once the screening of all the available material for each pilot project was finished, the relevant sources and answers to the questions of the framework were reported for each of the nine domains. This description included which information is available, where answers are partial or missing, pointing at the commonalities and challenges as well as the differences between the pilot projects. The answers to the questions of the framework are reported in chapter 7. Inspiring practices from the pilot projects were also extracted from the project material and are included in Annex No. 7, as practical examples of implementation, which could be replicated elsewhere.

Chapter 8 then critically looks at the pilot projects contribution to the implementation of Article 12, following the structure of the nine domains of the framework. It highlights the research and policy gaps to be explored by future pilot projects.

A number of additional topics (which did not answer to the questions of the framework) were detected during the analysis of the documentation and were reported thematically in addition to the domains of the framework. Such additional data was collected in the same way as for the framework domains. These additional topics will also be presented in Chapter 8.

5.2.3 Challenges encountered during the data analysis

The process of reporting into the template was a challenging exercise which needs to be described and reflected here. The answers reported in the template are often partial or incomplete answers to the questions. The difference between the theoretical questions of the framework, based on the literature about Article 12, and the practical activities of the pilot projects explains the difficulty in reporting data. Therefore, there is often a gap between the questions and the answers. For example, to answer the question of whether pilot projects have encountered people who refuse supports, only a case study, based on practice, has been included as an answer to the question. There was not enough data to generalise information from one project or to draw any conclusion. The case study nevertheless belongs to this domain of the framework, and it shows that one pilot project at least has dealt with the issue of people who refuse support. Sometimes the selected element was a very general comment, such as for example on the costs of support. The framework includes the question of whether the pilot project undertook an analysis of the resources needed to create a support network for people who have no relations or are socially isolated. Several pilot projects expressed some thoughts and concerns about the timeframe and the resources related to the creation of a support network for people who have no relations. Their reflection shows that the topic has not been ignored but they did not have the means to conduct a real analysis of the resources and the costs needed. Therefore, a comment was included in the template under cost of support.

Last but not least, it is important to note that advocacy work was often described by the project staff during the interview but is not part of the written material developed by the pilot projects. On the contrary, the social work has been described in different practical guidance material. Both sources thus appeared complementary and brought a comprehensive understanding of the project.

5.3 Methodological issues

Specific issues need to be raised in relation to the methods and the data analysis: the languages and cultural context as well as the position of the researcher.

5.3.1 Language and cultural issues

The preliminary survey and the questionnaire for the interview with key informants was written in English. The survey was also completed in English by all the informants.

The interviews took place in English but in the case of Columbia and Czech Republic the interviews took place respectively in Spanish and in Czech. The researcher translated the questions before the interviews took place.

The interviews were transcribed in the original language and were coded then in English in the excel table reporting answers to each of the question of the framework. The interview in Spanish was reviewed and proof-read by a Spanish native speaker.

The project documents were all in their original language (English, Spanish and Czech) with the exception of the documents of the Bulgarian pilot project which were available in English. For the purpose of consistency, the vocabulary used in the translated texts has been changed in some cases, to reflect the words used in this thesis.

Pilot projects included in this research took place in different parts of the world where the socio-economic and cultural environment is very different. The researcher has tried to reflect and take into account these specific aspects in the analysis. For example, in South America the issue of legal capacity also relates to safety issues - gaining autonomy and living independently relate to safety and security of the person and go much beyond questions of abuse (in terms of finances or contracting), as it is traditionally viewed in the Europe and North American context – in which the researcher is evolving. The gender aspect of supporters emerged as a key topic in both pilot projects in South America and is the object a specific subsection in Chapter 8. Another example from the pilot project in Zambia is the role of the community. That includes a much larger group of stake-holders, such as the Church representatives and traditional leaders. Their partnership is crucial in Zambia in terms of community involvement and to achieve system changes.

5.3.2 Researcher’s position and reflexivity

The researcher’s experiences in the field of legal capacity and in implementing a pilot project are likely to have informed and shaped the process of data collection and analyses. The questions used in the interviews are likely to be influenced by the researcher’s experiences and difficulties faced in her own pilot project. During the interview, some secondary questions or reflections were made as a reaction to this experience.

Although the research tried to analyse data with the maximum objectivity, her own views and her – maybe unwarranted - comparison through her own experience may have influenced the data collection and analysis.

On the other hand, the researcher’s experiences might have helped understanding the complexity of the issue of supported decision-making and the importance of combining several types of expertise (legal, social, communicational) to implement supported decision-making into practice. It might have helped to understand the difficulties faced by pilot projects – especially in terms of creating a change of culture - but also to identify innovative and specific aspects of each pilot project – as several projects used similar methods or paths at first glance. And it also meant that the researcher had rather high expectations in terms of results and impact of pilot projects, as she believes in the value of supported decision-making, as a human right and its potential for both individuals and for the society.

The direct involvement of the researcher in a pilot project allowed the identification of other pilot projects and their leaders, which would have been difficult otherwise due to the lack of visibility of many projects. It has also probably facilitated the contact with interviewees.

At the same time, the researcher made efforts to keep the maximum distance from her own work and analyse other projects without the prism of her own work. Regarding the pilot project on which the research had been involved, several years had elapsed and so this distance helped the researcher to read the materials again with a more objective lens. In addition, the application of a framework of analysis which was consistently used to identify and extract relevant data for all projects was intended to reduce any impact of the researcher’s familiarity with one project. Efforts have been made to avoid personal reflections and memories in the data collection phase to compare projects in the same way.

Specifically, her biases included a belief that guardianship is unnecessarily restrictive for adults with disabilities and that alternatives to guardianship are more appropriate.

5.3.3 Limitations

The last chapter will be discussing the limitations of this thesis and its methods, however, some specific limitations relating to the data collection needs to be reflected in this Chapter.

The interviews took place in the course of the project and therefore interviewees had not always had the opportunity to reflect on the achievements and the current activities of the project. Interviewees usually shared positive or negative emotions due to the situation in which they were currently working (e.g.: successful campaign or advocacy or change of government)

The interviews took place with only one or two interviewees, who by their coordinating role could speak about all the aspects of the project – social work, legislative work, strategic litigation, advocacy and work with the media. There was no contact between the researcher with pilot project participants or facilitators. Observation and interviews with pilot project participants would have brought another view on the process of the pilot project. This is why evaluation reports or other reports including the views of participants, both persons with disabilities and their supporters have been such a valuable input to this work. Some of their concerns, fears and questions are reflected in Chapter 8 – in the emerging topics which came out of the documents analysed for this study.

The next chapter presents an initial mapping of each pilot project included in the research and describes its objectives, characteristics and outcomes.

6 Overview of the Pilot Projects Selected for the Study – Objectives, Characteristics and Outcomes

This chapter provides an overview of six pilot projects which are analysed in detail in Chapter 7 with the framework presented in Chapter 4. Section one introduces the specific characteristics of each pilot and conducts an initial mapping of the projects, including the different types of material they produced. Section two provides a summary of the design of the projects and of available quantitative data.

6.1 Objectives, characteristics and outcomes of the pilot projects

In this section, each of the six pilot projects is described through a brief presentation of its development and activities, key facts about the project (summary table in Annex No. 5), information about the project design, based on the interviews (see Annex No. 4) and the material available (see table No. 1), as well as its impact and results.

6.1.1 Pilot project in Bulgaria

Bulgaria is a country of Central and Eastern Europe still fighting with the aftermath of the communist regime. A number of reports and case-law have highlighted the difficult situation with plenary guardianship (e.g. ECHR [2012], Stanev v. Bulgaria) and institutionalisation of people with intellectual and psychosocial disabilities (Šiška and Beadle-Brown, 2020). According to data from 2012 there were 7,040 people under guardianship (6,249 under full guardianship and 791 under partial guardianship); 3,679 live in long-term residential care (Turnpenny et al., 2017), for a population of circa 7 million inhabitants[67].

The pilot project in Bulgaria started in 2012 and is in fact the result of several projects ("Empowerment of Persons with Intellectual Disabilities", "Empowerment of Persons with Intellectual Disabilities – Next Step", "You Have the Right to Decide", "Change through Knowledge") progressively expanding the work on the practical implementation of a supported decision-making model. It lasted several years and it still continues in order to achieve system change. The project involved people with psychosocial and intellectual

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[67] 6,951,482 persons as per 31 December 2019, according to the Bulgarian National Institute of Statistics available at : https://www.nsi.bg/en/content/18125/%D0%BF%D1%80%D0%B5%D1%81%D1%81%D1%8A%D0%BE%D0%B1%D1%89%D0%B5%D0%BD%D0%B8%D0%B5/population-and-demographic-processes-2019, last accessed 21/1/2020

disabilities, both groups participating through their representative organisations[68] with the overarching work of the Bulgarian Centre for Non-Profit Law (BCNL). In the case of Bulgaria, the pilot was scaled-up to become a new standard programme proposed in some regional branches of the partners. People involved in the project were both people excluded from the community (e.g.: living in remote congregated settings) and/or people who are seen as not able to make decisions. Activities of the projects included individual and social work, strategic litigation (restoration of legal capacity), as well as campaigning and advocating for changes. Although a draft law was ready to be discussed in the Parliament, because of several national political twists and turns, as of the end of 2020 the law has not yet been adopted, thus blocking the comprehensive realisation of the scaling-up phase.

Key facts:

Date – length of the project	People with support needs involved	Supporters involved	Type of support
2012–2014 2014–2016 2017–2018	150 people (people with intellectual and psychosocial disabilities)	Family members, friends, community volunteers (unpaid)	Non statutory agreement

Project objectives:

The project was a 6-year initiative including several objectives. The project developed a mechanism for re-evaluating the project objectives. So, the specific objectives changed over time as part of the process. The pilot was very dynamic from the advocacy point of view, to be reactive to the political context and situation (BG_INT_1).

- Overall objective: legal capacity for all.
- To secure the legal background for legal capacity (CRPD ratification)
- To start the pilot programme and provide new instruments.
- To create an environment in which these achievements are recognised by the legal, the social and the parents’ communities.
- To elaborate on all these achievements from the grassroots level and to draft a new law.

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[68] BAPID, the Bulgarian Association of People with Intellectual Disabilities, GIP – Global Initiative on Psychiatry – Sofia and NOUMHS, the National Organisation of the Users of Mental Health Services.

- To gain public support for the draft law, to organise a nationwide campaign, to reach professional groups and stakeholders beyond the traditional sphere of work of the partners' organisations: "*we set as a goal to attract new people, who are not related [to legal capacity]*." (BG_INT_1)
- To secure support from the community and to put pressure on decision makers to adopt the new draft law (national campaign including petition).

Project participants and their recruitment:

Partner organisations recruited from among their members and service clients, both people under guardianship and with full legal capacity. Interested persons could participate by signing an agreement on supported decision-making and also when possible, it was also signed by their supporters or their guardians. From a legal point of view, half of these documents did not have legal value; the project leader describes it as a "decoration of support", but formalising the support gave confidence to the participants and created liability to the supporters. BAPID also developed easy-to-read versions of the agreement (BG_INT_1). However, recruitment was not easy, as it was hard to make people believe that supported decision-making has a different value and different consequences, especially "*to have the trust of the families*" (BG_INT_1).

Project material:

The project development and outcomes are described in several written publications. A **Guide-Book to rights enforcement** provides practice guidance for staff supporting people with intellectual and psychosocial disabilities in exercising their human rights. The document describes and offers a template to create the conditions for supported decision-making for individuals. It includes material for facilitators and different templates adapted to each target group. The **New formula for capacity to act** describes how to make system changes to ensure that everyone can exercise his/her rights regardless of his/her disabilities. It includes detailed proposals for a law reform, including substantive and procedural legal changes. The **draft** "**Natural persons and support measures act"** illustrates the work in progress of the legal development at one specific date. It represents a concrete result of the advocacy work done by the organisations. The document **Challenging the law and policy framework for people with intellectual disabilities and mental health problems to exercise their rights what, where and how** proposes a comprehensive approach to the problem, tackling all policy areas influenced by the issue of supported decision-making, such as accommodation in residential services and housing, legal aid, access to services, choice and organisation of treatment, employment or management of property, finance, private funds. A **Cost Benefit Analysis of**

Supported Decision-Making completes the series of policy documents by providing an overview of financial and non-financial benefits of a new system of supported decision-making.

Impact and results

For both implementing organisations, the project has changed the way are working: “*(it) changed their services provision in such a way that now it is an irreversible process. It was a huge moment for them to reflect and really to see what they do and where they want to go. It's really a process.*” (BG_INT_1)

The most important result is the process of elaboration of the draft law, which introduces the pilot project ideas. It is a long-term achievement, a bottom-up process in which the pilot project team and participants have taken the leadership from the beginning to the end.

The project has had impact on several groups of people from different professions, thanks a two-fold strategy: first, they attracted professionals to follow the pilot programmes, to see first-hand outcomes, and secondly, they found allies in these different professional groups (doctors, social policy experts, legal experts) to speak, present and share the project ideas and results.

In terms of impact on a larger public, the project partners created a petition to put pressure for the adoption of the law and launched a huge national and communication campaign, led by 12 welfare organisations. They gathered more than 12,000 signatures for that law. From a communication point of view, it was a huge promotion of the idea of universal legal capacity.

6.1.2 Pilot project in Peru

Peru is the third largest country in South America. In Peru, formal guardianship is not so common. Families of people with intellectual and psychosocial disabilities may be “forced” to initiate guardianship proceedings because of administrative procedures to access social security or pensions (PE_INT_1). For those who resist the procedure, in practice they face many barriers when it comes to banking, insurance or access to different allowances (Vasquez, 2015). According to the Peruvian alternative report to the CRPD Committee, the number of people under guardianship in Peru is roughly estimated at about 8,000[69] people for a population of 32 million inhabitants[70] of which more than a million and a half has a disability (Vasquez, 2015).

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[69] Estimation given by Bureau of Disability Rights and Human Rights Coordinator (CNDH) formed by 19 civil society organisations for the preparation of the List of Issues Prior to Reporting to the CRPD Committee.

[70] Perú: Estimaciones y Proyecciones de Población Total, por Años Calendario y Edades Simples, 1950–2050" [Peru: Estimates and Projections of Total Population, by Calendar Years and Simple

The pilot project in Peru was relatively short and involved only people with Down syndrome, the natural constituency of the leading organisation, the Peruvian Society of People with Down Syndrome [Sociedad Peruana de Síndrome Down, SPSD]. The project was realised in two socio-economically different districts of the capital city, Lima (almost 10 million citizens in 2020). One important aspect in the realisation of the project, intrinsically linked to the issue of autonomy of participants was the safety issue: *"the capacity of moving around in the community. Feeling safe"* (PE_INT_1).

It is also important to note that other initiatives on supported decision-making were realised in Peru in parallel to this project, and altogether they have contributed to the recent law reform that passed in Parliament. In 2018, the Peruvian Government published Legislative Decree No. 1384, which recognises and regulates the legal capacity of persons with disabilities. The legislative decree (which holds the same status as a law) adopted, reforms the Civil Code, the Civil Procedural Code and the Notary Act. It recognises the full legal capacity of all persons with disabilities, abolishes guardianship for persons with disabilities, removes restrictions on their legal capacity (e.g. to marry or to make a will), and introduces different regimes for supported decision-making. Legislative Decree No. 1384 also recognised the right to reasonable and procedural accommodation in courts and notary offices[71].

Key facts:

Date – length of the project	People with support needs involved	Supporters involved	Type of support
1.5 year project	20 people with intellectual disabilities (living in families)	Family members + volunteers	Non statutory agreement

Project objectives:

The project pilot included the following five goals:

- To empower people with Down syndrome and intellectual disabilities as advocates

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Ages, 1950-2050] (PDF) (in Spanish). National Institute of Statistics and Informatics. September 2009. https://www.inei.gob.pe/media/principales_indicadores/libro_1.pdf (last accessed 12/3/2022)

[71] See the translation of the Decree done by the disability NGO SODIS, available at https://sodisperu.org/sites/default/files/2021-05/Legislative-Decree-No-1384-Peruvian-legal-capacity-reform-2.pdf (last accessed 12/3/2022)

- To identify cases of discrimination or cases where the rights related to legal capacity were not respected
- To identify or help settle community-based networks of support
- To work with municipalities – to identify or help develop local networks, near to the population
- To provide case studies that can put light on some of the administrative barriers (when a person is not under guardianship)
- To change the Civil Code

Project participants and their recruitment:

The project pilot recruited 10 young people in each of the two districts of Lima. The process was tight and recruiting more people would have been difficult. The project leader reported that families were afraid of change. "*Because when speaking about self-determination, and people taking their own positions and giving them freedom, it means that we as families are losing control. I think that's one reason and the other reason is overprotection. Because we think they are like children even if they are 40 or 50."* (PE_INT_1). The project leader also added that out of 20 perhaps two or three left the project, because their parents said that "*their child was not as obedient as they were before*" or "*they started to say they want to live on their own or have a partner*".

To participate in the projects, four conditions were posed to the young people:

- To make sure that they want to take their own decisions and have their own voice, their own dreams and fight for them
- To have their identity card with them
- To have a cell phone with them, because it is safer and gives more confidence both to the young adults and the families
- To sign an agreement or a letter to say they agree with these conditions

Project material:

The project developments and outcomes are mainly described in an **External Evaluation Report**, based on interviews with project participants, their families and representatives of the municipal offices for disability and as well as focus groups with staff realising the project and project reports to the donor.

Impact and results:

In terms of results, the project pilot developed a tool kit to deliver workshops, including sixteen sessions for people with intellectual disabilities and 10 sessions for families. This material concentrates the know-how of the pilot project.

In terms of impact, it can be seen mainly at the individual level: persons with intellectual disabilities were able to identify their own dreams, to have a voice and they learned that there is someone else besides their mother they can turn to.

6.1.3 Pilot project in Colombia

Colombia is a country of South America, with over 50 million inhabitants and one of the most ethnically and linguistically diverse countries in the world. There are no reliable statistics about people with disabilities in Colombia. Based on UN international figures, a rough estimation of over 4 million people with disabilities are living in Colombia[72], many of them in poverty. Colombia inherited the Roman law and Civil Code tradition, therefore plenary guardianship (*interdicción*) was instituted for over 150 years. In 2009, Colombia reformed the regime of legal capacity: law 1306 of 2009 used a more respectful language to refer to persons with disabilities and provided more modern mechanisms for patrimonial and financial protection (Correa-Montoya and Castro-Martínez, 2016). In 2019 however, Colombia adopted a new law, law 1996, on the exercise of legal capacity by adults with disabilities, putting an end to plenary guardianship, and other practices in violation of the CRPD, like sterilisation of women with intellectual disabilities.

The Colombian pilot project managed to mobilise several resources to realise their project. A solid network of two organisations representing people with intellectual and psychosocial disabilities implemented the project with a university legal clinic (PAIIS)[73]. At the level of individual work, the project staff used a large panel of methods (semi-structured interviews, focus groups, PCP instruments, observation, questionnaires and rapid diagnosis) to gather in-depth knowledge of the participants and their environment with the objective of creating with them a personalised support system based on their life plan. It is important to note that most participants in the first phase were people from Bogotá, the capital city. They have also used online training courses to outreach and train organisations of people with disabilities and replicate, thanks to this online training, the pilots. The methodology the project designed was therefore tested in other parts of the country. Finally, in terms of advocacy, the case of Columbia is very positive compared to other pilots. In 2015, a roundtable to

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[72] See the estimation by Jairo Clopatofsky, Government Counsellor for the Participation of People with Disabilities in a press article: https://www.elnuevosiglo.com.co/articulos/09-2019-colombia-suprime-interdiccion-legal-personas-discapacitadas (last accessed 12/3/2022)

[73] Asdown Colombia for people with intellectual disabilities and Nodo Comunitario de Salud Mental for people with psychosocial disabilities, with the support of PAIIS, which is a public interest legal clinic of the Faculty of Law of the University of the Andes; PAIIS stands for the Action Programme for Equality and Social Inclusion – Programa de Acción por la Igualdad y la Inclusión Social.

prepare a new law to end incapacitation in Colombia took place. The drafting of the law took place over the course of 2 years: intense meetings with international experts and different events convinced participants that, beyond a diagnosis, people are able to take decisions (showing the difference between mental capacity and legal capacity). Project staff and participants were involved in this process as well as PAIIS and Rundis, a network of legal advice formed by the Ministry of Justice, joined by 67 universities around Colombia (CO_INT_1). Very soon after the end of the project, the new law was adopted, opening up a new era for people with disabilities.

Key facts:

Date – length of the project	**People with support needs involved**	**Supporters involved**	**Type of support**
3.5 years in total: February 2015-December 2016 March 2017-October 2018	36 people: • 20 with intellectual • 16 with psychosocial disabilities	Mainly family members	Constitution of a support network (symbolic instrument)

Project objectives:

The Colombian project was framed with the belief that decision-making is strongly linked to the existence of mechanisms and ways of living in the community, thus linking Article 12 with Article 19 of the CRPD entitled Living independently and being included in the community.

The project thus pursued the following objectives:

- To strengthen the knowledge about decision-making in relation to Article 12 and legal capacity
- To identify the supports people have/need to make their decisions, the supports people require to exercise their legal capacity
- To identify family support
- To identify community supports that people require to make their decisions (holistic approach of the environment)

Project participants and their recruitment:

The objective of the project was to include a wide range of participants with different characteristics and a template was designed to record the heterogeneity of each of the possible participants. Some of the criteria used to determine this were: the gender of the participants, level of schooling, socio-economic level, family networks, labour inclusion, as well as people incapacitated and people with full legal capacity. From the data available, the participants from six different boroughs of Bogotá were mixed from the perspective of the main variables evaluated. While the project staff did not mention problems with the recruitment, they stated that they worked with 40 people in the first phase. But during the process some people left for different reasons. They ended up with 23 people in the first phase: 11 persons with psychosocial disabilities and 12 with cognitive disabilities.

Project material:

The project development and outcomes are described in several documents. First of all, the **project reports to donors** were made available to the researcher. There are four monitoring reports containing a detailed description of the activities and the work done, including individual work with participants and the methods used with them. An **academic article** jointly written by the staff of the project describes the work to set up individual systems of support, the methods used, and draws some conclusions on the experience. Two **modules of the online training course** describe in simple terms the CRPD principles, legal capacity, the difference between substituted and supported decision-making for facilitators (people who will be working to set up individual networks). A **policy document** called “The exercise of legal capacity: Practical guide for its application” provides: an overview of the situation of legal capacity in Colombia; possible alternatives to support people with disabilities in the field of finance and assets management, as well as health care; and how to create a system of support for people with intellectual and psychosocial disabilities. The policy document is written in plain language and includes templates for individual work. Last but not least, **law 1996** of 2019 on the exercise of legal capacity by adults with disabilities is included in the project material. Although it is not a direct outcome of the project, it was definitively influenced by the project development.

Impact and results:

In terms of results, the Colombian project developed several accessible training and information materials, including a practical guide of possible alternatives in the field of finance and assets. The strong collaboration with law faculties around the countries gave solid expertise in terms of legal work to the pilot project partners. And it constituted a wide-spread partnership for scaling-up the pilot project ideas and experience.

In terms of impact, the results of the pilot project and the testimonies of project participants about systems of support as alternatives to guardianship were presented and heard at the Ministry of Justice. This created an impulse for a series of events and collaborations promoting the idea of universal legal capacity and it definitely influenced the content of the draft law, adopted in 2019.

6.1.4 Pilot project in the Czech Republic

The Czech Republic is a country of Central and Eastern Europe which, similarly as Bulgaria, still struggles to reduce the high number of people with intellectual and psychosocial disabilities living in large residential institutions and under guardianship. In 2011, 5,741 people with partial guardianship and 26,520 with plenary guardianship were counted according to the statistics of the Ministry of Interior, thus being among the countries with the highest numbers per inhabitants (MDAC, 2013). In 2014, a new Civil Code entered into force. It brought several fundamental changes. The law prohibits plenary guardianship and proposes several instruments as alternatives to guardianship: 1) supported decision-making in the form of decision-making assistance agreement, 2) representation by a member of the household, 3) guardianship without restriction of legal capacity. The Civil Code continues to make it possible to partially restrict legal capacity *as a matter of last resort*. In practice however, the number of people with limited guardianship living with permanent residence in the Czech Republic is quite stable, at around 36,000 people[74]. Between 2014 and 2016, guardianship without limitation of capacity has been applied in 5,572 cases. This is clearly the most frequently used alternative to partial guardianship. 1,338 decisions were made to approve representation by a member of the household. And 155 decisions approved a decision-making assistance agreement.[75] Although partial guardianship is still by far the most commonly used tool, it is clear that some local courts deal with these alternatives and others not at all[76]. In court proceedings, the court needs to determine whether a "mental disorder" is present. The presence of mental disorder is confirmed by an expert assessment. However, these expert opinions

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[74] Between 2014 and 2016, the sum of all cases of partial guardianship comprised a total of 29,012 decisions while only 2,154 cases of restoration of legal capacity can be found. See Ministry of Justice *Rozhodování o svéprávnosti: Statistická data z období 2014 – 2016 s komentářem*, 2018 (Decisions on legal capacity: commented statistical data from 2014 –2016*)*, published in 2018 available at: https://www.justice.cz/documents/12681/724488/Zpr%C3%A1va+ke+sv%C3%A9pr%C3%A1vnostem_final_pro+web.pdf/82964de5-60af-4a24-bb78-ba6c0ed48586 (last accessed 20/1/2021)

[75] Pages 14, 18 and 20 op. cit.

[76] The maps with the information are available at: https://www.justice.cz/documents/12681/724488/Zpr%C3%A1va+ke+sv%C3%A9pr%C3%A1vnostem_final_pro+web.pdf/82964de5-60af-4a24-bb78-ba6c0ed48586 (last accessed 20/1/2021)

are very problematic[77], as described in a document of the pilot project (SPMPČR, SNN, NRZP, 2020).

The pilot project in the Czech Republic, resulting from a series of projects called Black and White (I to IV), started just before the Civil Code change and accompanied this change, thus trying to give some substance to a reform which had not been prepared thoroughly. Both organisations leading the project[78] work primarily with people with intellectual and to a certain extent with psychosocial disabilities. The project focused on raising awareness about the negative aspects of guardianship, especially among professionals and family members and concentrated on how to make the best use of the new legal provisions in practice. Strategic litigation and mainly preparation of the material for court cases by a social worker-lawyer duo was one of the main project activities, which is now usual practice in both leading organisations. After the adoption of the Civil Code, for many years a discussion took place about the opportunity to adopt law on guardianship (and alternatives to guardianship) but for political reasons and due to disinterest this plan was abandoned despite DPOs' pressure. Therefore, the project activities worked to change the practice within the existing legal framework.

Key facts:

Date – length of the project	People with support needs involved	Supporters involved	Type of support
2012 – 2019 (4 phases)	20+ 21 + 13 (54 people in total) + people involved in research (29 + 10) 103 people	Family members, friends, community volunteers (unpaid)	New Civil Code legal instruments, including decision-making assistance agreement

Project objectives:

The overall objective of the 6-year initiative was the implementation of Article 12 in the Czech Republic. Other objectives evolved with every phase of the projects (Black and White I to IV):

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[77] See Milena Johnová, Dana Kořínková and Jan Strnad, *Právní případy zaměřené na vrácení svéprávnosti a využití podpory při rozhodování*, QUIP 2017, (Legal Cases restoring legal capacity and using supported decision-making, QUIP, 2017) available at: https://www.umluva.cz/res/archive/000151.pdf?seek=1503304657 (last accessed 20/1/2021)

[78] The projects were implemented in partnership by QUIP and SPMP ČR, which stands for *Společnost pro podporu lidí s mentálním postižením v České republice, z.s.* (Inclusion Czech Republic).

- To build evidence and arguments about the negative impact of substituted decision-making and guardianship
- To test new methods of work with people with intellectual disabilities, including methods combining social and legal work, and methods to build or extend circles of support
- To make the best use of the new instruments in the Civil Code, implement the new legal provisions as close as possible to the spirit of Article 12 CRPD
- To create and maintain a Learning Community, a platform gathering social services, DPOs, families and people with disabilities to discuss implementation in practice, through case clinics and exchange of good practices and cases studies
- To make proposals for reforms – campaigning for a better implementation of Article 12
- To share ideas among NGOs, DPOs, judges, lawyers, academics thanks to the creation of the Alliance 12 platform of stakeholders
- To train judges, social workers and family members on supported decision-making and the new provisions of the Civil Code
- To use media to publicise information about legal capacity, supported decision-making, the right to vote and other aspects linked to legal capacity

Project participants and their recruitment:

Beyond their disabilities, participants were not recruited on the basis of specific characteristics. The interest in the project was constantly high as people had to deal with it because of the new Civil Code – all persons under guardianship had had their status reviewed with the New Civil Code between 2014 and 2018. Project staff therefore looked mainly at the motivation of each individual: for example, people who wanted to change something in their life, to do something with their legal capacity people who did not want to be under guardianship, people who needed help to set up communication methods.

However, some participants dropped out of the project. Often it was linked with the refusal by a guardian or a family member to support the wish of the person, deal with risk assessment or to find a compromised solution. This is why the first conversations were so important to clarify the expectations and the common understanding of the principles of the pilot project work (CZ_INT_1).

The project included people from all over the country – the majority was from the regions of Central Bohemia and Prague; participants, however, represented a good mix of people living with their families and living in residential care (both large residential facilities and supported housing).

Project material:

The project development and outcomes are described in several documents. First of all, **the Black Book, the other side of the restriction of legal capacity** is a policy and legal document describing the human rights violations around guardianship, the procedural issues related to guardianship proceedings and the problems in its application in the everyday life of people with disabilities. The policy document called the **White Book** is by contrast a pamphlet for reforms of legal capacity and proposes concrete recommendations for changes. A large document called **Support in decision-making and legal proceedings instead of restricting self-determination** (methodology) provides practice guidance and examples of individual work (including instruments for it) to set-up support networks. An **evaluation of the experiences of participants in using decision-making instruments** provides an overview of the situation of project participants with their legal capacity a few years after they started to use a new instrument. From a legal perspective, a document called **Legal Cases of Legal Capacity Restoration and the Use of Support in Decision Making** describes the experience of project staff during judicial proceedings of project participants. Based on experiences gathered during the project, the document **Ethical and methodological principles of providing support in decision-making and legal proceedings** provides supporters with practice guidance. Similarly, a policy document called **Safeguards** gathers concrete proposals in eight areas to reform the system. The last documents included **sample documents** produced by the project: easy-to-read information about banking; sample legal documents, including a three-party agreement with a bank, client, and supporter(s), and an example of a trust fund contract. Finally, the researcher had access to project applications and **project reports** to donors.

Impact and results:

The pilot project never succeeded in putting amendments or an additional law on alternatives to guardianship on the table, but it contributed to creating a community of people who are pushing for a better implementation of the new Civil Code. The community, led by NGOs but also some lawyers and judges pushed for small changes both by implementing the principle of guardianship as a matter of last resort and using alternatives where possible and in terms of coherent and uniform application in the different areas of the country by sharing good practices and standardised procedures. Changes are slow but the change of paradigm progressively spreads out in the social and legal communities.

6.1.5 Pilot project in Zambia

The Republic of Zambia is a country of south-central Africa, with an estimated population of 18,384,000 inhabitants in 2020[79]. Zambia has a plural legal system consisting of general law based on English law (common law) and customary law[80]. Zambia, like most common law countries, has a dual system, therefore, the CRPD was domesticated with the enactment of the Persons with Disabilities Act in July 2012. However, the Persons with Disabilities Act did not repeal the Mental (Health) Disorders Act, which allowed judicial authorities to put persons with disabilities under guardianship. The Mental Disorders Act inherited from the colonial legacy dated from 1949 and had not been significantly revised until 2019 when the Mental Health Act was adopted (Beaubien, 2015).
The Mental Health Act of 2019, although considered as a more progressive piece of legislation, is problematic because of the confusion of mental capacity with legal capacity, thereby denying persons with disabilities their right to legal capacity [81]. Section 4 of the Mental Health Act requires a mental capacity test as the premise for legal capacity, thus denying the presumption of capacity. Section 4(2) states: *"Where the nature of the mental illness, mental disorder or mental disability results in the absence of mental capacity of that mental patient, the mental patient shall not enjoy legal capacity and is legally disqualified from performing a function that requires legal capacity."* This paragraph generates a mischief by creating the concept of a "legally disqualified" person (Kayumba, 2020). So, if a court declares an individual as not having legal capacity under section 4, the person becomes disqualified for all legal purposes (DRW, 2021).

The Zambian project took place before the legal change and should get credit for opening up the discussion and raising awareness about legal capacity at several levels in the country. They engaged at local and national levels with all important sectors and political representatives, reaching out of the "disability" community. They also worked with "ambassadors", people with psychosocial disabilities who received a distinction given by the Zambian State (5 people across the country) to fight against myths and preconceived ideas about people with disabilities.

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[79] See 2019 Revision of World Population Prospects prepared by the Population Division of the Department of Economic and Social Affairs of the UN Secretariat, available at: https://population.un.org/wpp/ last accessed 28/1/2021

[80] Customary law consists of the customary laws of each of Zambia's 73 ethnic groups and is not a unified system

[81] About the new law see the article by Felicity Kayumba available at: https://www.commonwealthlawyers.com/africa/a-legally-disqualified-person-the-mischief-created-by-zambias-parliament-in-the-2019-mental-health-act-by-felicity-kayumba-kalunga/ , last accessed 4/7/2020

Key facts:

Date – length of the project	People with support needs involved	Supporters involved	Type of support
2-year project (2016-2018)	• 30 persons with psychosocial disabilities • 30 people with intellectual disabilities	Family members + friends + volunteers from the community	Informal support network

Project objectives:

The main project objective was strengthen the capacity of persons with psychosocial and intellectual disabilities, their families, their communities to develop effective community-based methods and other supports, which enable people to exercise legal capacity without social and economic exclusion.

Project participants and their recruitment:

The project aimed to recruit 10 participants for each group in three sites (Kazungula, Mansa and Shan'gombo). So, in each project site there were two groups: one of people with intellectual disabilities; one of people with psychosocial disabilities. The project leaders engaged with various DPOs working with both groups in those communities to recruit the pilot participants (ZA_INT_1).

The pilot project had the ambition to include diverse participants with different educational backgrounds (lower and higher education), economic status, gender and ages, including young and older people (from 18 to 59 years old) (ZA_INT_1).

Project material:

No additional material was made available to the researcher[82].

Impact and results:

The project raised awareness about legal capacity and supported decision-making in Zambia, by identifying existing discriminatory policies and laws to be reformed and reviewed but also by undertaking community research and pointing out the stigma and discrimination in the communities where the pilot project was implemented.

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[82] Emails sent as a follow-up to the interview remained without response. But because of ZAFOD staff turnover, communication was disrupted.

The pilot project had some impact in the local communities: for the first time in their lives people were able to freely indicate what their dreams were, what they aspire to do in the future; and the pilot project has also been able to bring in committed people, mainly families and supporters from the community, who are learning to provide support according to the desires of individuals.

6.1.6 Pilot project in New York City, USA

The last pilot introduced in this Chapter is the pilot run in New York City, the largest city in the United States. The USA is among those few countries in the world who have not yet ratified the CRPD. But it has not discouraged a number of pilot projects nor prevented several states from passing legislation on supported decision-making agreements[83]. Data from the National Core Indicators 2017-2018 In-Person Survey (IPS)[84] indicate a wide range among states of individuals reported to have full or partial guardianship– from 5.5% in one state to 89.0% in another. Guardianship legislation indeed varies from one state to another, but several procedural provisions improved the status of the people in guardianship procedures in the 80s and 90s. In 2017, the Uniform Law Commission approved supported decision-making as a less restrictive alternative that must be considered before guardianship can be imposed. In New York, the Surrogate's Court Procedure Act is however still based on a simple criterion of diagnosis of intellectual or developmental disabilities and the judge's opinion that it is in the "person's best interest" to proceed with guardianship (Pell, 2019).

The Supported Decision-Making New York (SDMNY) pilot project is a five-year initiative going on until 2021[85]. The project is run by a consortium of collaborating institutions: Hunter College of the City University of New York (CUNY) serves as the lead agency[86]. Because it started after other US and English-speaking countries' pilot projects, it benefited from previous experiences and therefore there was the ambition to go further and to open-up more difficult questions, especially in terms of sustainability. This project has been well documented and promoted around the world by Kristin Booth Glen, a

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[83] https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/ last accessed 20/1/2021

[84] National Core Indicators Data Brief, What Do NCI Data Reveal About the Guardianship Status of People With IDD?, April 2019, https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf last accessed 28/1/2021

[85] Before submission of this thesis, the project website announced the information that the pilot project was granted a three year extension (one year had been the original request because of the COVID-19 pandemic).

[86] Other partners include: the New York Alliance for Inclusion and Innovation and The Arc Westchester. Disability Rights New York (DRNY), the state protection and advocacy agency, serves as the legal resource. https://sdmny.hunter.cuny.edu/about-sdmny/partners/ (21/10/2021)

former guardianship judge and the leader of the pilot project, who has written academic articles along with the implementation of the project and has shared theoretical reflections around the pilot implementation. The advisory board of 54 members, including several academics and disability leaders in the US and internationally also gave the project a particular aura.

The SDMNY project worked with people with intellectual and developmental disabilities as well as people with autism and the staff has taken the approach of working solely with the "decision-maker" at the beginning (bringing in supporters at a later stage). When writing this chapter, the project had not yet been through implementation of the supported decision-making agreements, as the time for creating an agreement was longer than foreseen.

Key facts:

Date – length of the project	People with support needs involved	Supporters involved	Type of support
5 years (2016 – 2021)	79 people with intellectual and developmental disabilities and autism at the end of Year 3	Family members, guardians, staff, friends, community volunteers	Notarised agreement (and health care proxies if the person wishes so)

Project objectives:

The overarching goal is to provide data and narratives to inform reforms to state law to advance the use of supported decision-making as an alternative to guardianship.

This includes a scaling-up expansion of the model:

- To develop and test a facilitation model over approximately eighteen months in New York City
- To expand the model to Westchester County with the assistance of consortium partner, The Arc Westchester
- To utilise the (by then) tested and refined model to roll out pilots in three to five geographically diverse sites across New York State
- To develop and create "learning communities" comprised of representatives from provider and stakeholder organisations in the targeted geographic areas to help plan implementation of the pilots there, and, optimally, to carry "learnings" from the process back to their organisations to create a multiplier effect.

Project participants and their recruitment:

The objective of the project was to recruit at least 135 people with intellectual and developmental disabilities for the pilot programme. As per 2019, 79 individuals with intellectual disabilities signed up for the pilot, however, 10 withdrew after signing up. The project staff aimed to outreach to a more diverse pool of individuals: people with more significant impairment, including those who do not communicate verbally, and to those with diverse ethnic and racial identities, socio-economic backgrounds, and experiences.

However, as described in the mid-term evaluation report, the recruitment process ended up being more difficult and time consuming than expected. Outreach information sessions were organised in different places. But the staff realised that one-time sessions were almost useless and they moved to developing long-lasting relationships with organisations: "*Building relationships and trust takes a lot of time but turns out to be really necessary*." (Pell, 2019). The staff also planned to involve a self-advocate in those recruitment sessions (Pell, 2019).

Project material:

The project development and outcomes are described in several documents. A mid-term evaluation report **Supported Decision-Making New York: Evaluation Report of an Intentional Pilot** looks at the perspectives of families and individuals with intellectual disabilities (concerns about guardianship, reasons for involvement in the project, changes related to guardianship and changes affecting the individual). Two academic articles written by Kristin Booth Glen describe the project developments at two different steps. The first article **Piloting personhood: reflections from the first year of a supported decision-making project** in the Cardozo Law Review describes some first lessons learned from the facilitation model. The second article in the Albany Government Law Review **Supported decision-making from theory to practice: further reflections on an intentional pilot project** describes further developments and mainly the challenges around recruitment of decision-makers, facilitators, and the process of facilitation. The article also explores the next steps that are required. Additional material includes **templates for facilitators**: they comprise a facilitation protocol, cheat sheet and worksheet for individual work for the three phases of the facilitation. Another available template is the Big Four Chart, which allows determining what the agreement has to contain. The last material available includes **presentations** done by the pilot project staff.

Impact and results:

The project will run for three more years than expected, so the results and the impact will potentially be much broader than what is reported here. However, the New York pilot has been well documented with the publication of academic articles describing the process and the lessons learned of the pilot project. This regular reporting and monitoring, including a detailed description of lessons learned, provide a solid evidence base for lawmakers but will also be useful for the design and implementation of other pilot projects around the globe. In terms of its size, its length and its partnership, the New York pilot is among the largest pilot projects. Both the staff and the external evaluator claimed that the pilot project model *"has proven to be a viable, less restrictive alternative to guardianship for persons with intellectual disabilities, benefiting participants by promoting autonomy, self-determination and inclusion"* (Booth Glen, 2019). The impact on both decision-maker and supporters is positive: decision-makers are more engaged, more skilled and experienced while supporters are learning to step back.

6.2 Summary of the pilot projects characteristics

This section provides a summary of the characteristics and key patterns of the pilot projects. First of all, as in those presented in Chapter 3, all the projects reported that they had a positive impact on the people who participated in the projects.

The description of the pilot projects shows commonalities in term of project participants and key patterns in terms of project design.

In terms of length, the pilot projects include a mix of rather short-term and long-term projects, covering periods from 1.5 years to 8 years.

In terms of the number of people with disabilities involved, the pilot projects were rather small and worked with a limited number of participants. The nature of the work with project participants is time-intensive, as it included in-depth social work and mapping of individual situations and environments, also with people who have communication barriers.

A common challenge for most pilot projects was the recruitment of participants. Most projects reported difficulties and extra-time needed to recruit people, especially where there was the ambition to include people with different levels of disabilities as well as diverse identities and socio-economic backgrounds. The most frequent arguments to explain this difficulty are the necessary time to build relationships and the need to find understandable arguments to step in for families and people with disabilities. The relative novelty of supported decision-making and the strong belief that guardianship is necessary (the pressure by the system to make guardianship a necessary step is explored in detail later in Chapter 9) are also barriers to the recruitment. For longer projects, the involvement of people with disabilities and families who have gone through the process already has been of great help to recruit at a further stage (BG_INT_1; CZ_INT_1; NY_DOC_1).

Most projects included both people with intellectual and psychosocial disabilities, but altogether the pilot projects included a higher number of people with intellectual disabilities. Although there is no disaggregated data about participants, people who might benefit more from making decisions with supports, like older adults with psychosocial and intellectual disabilities or people with severe and profound intellectual disabilities, were not the primary participants of the pilot projects. In all the pilot projects, a mix of people under guardianship and people who have full legal capacity has been involved. In the Czech Republic (16), Bulgaria (4) and New York (1), some people have recovered full legal capacity during the project, as a direct result of the project activities in some cases or indirectly.

Supporters have been predominantly family members, but also friends and other acquaintances (staff of social services) as well as volunteers from the community (e.g: neighbours). They were chosen by the participants to act as supporters, thanks to methods and tools for mapping support needs and potential supporters, a topic that is explored in detail in the next chapter. All of them were acting as volunteers and were not paid supporters.

With the exception of the Czech Republic, non-statutory legal agreements (created for the purpose of the project) were used. So, in practice they had no legal value, or did not offer a sufficient guarantee that the agreement could be enforced, while restrictions of legal capacity still apply. In the case of New York, the agreements were notarised, which gave them legal validity, but only to a certain extent, since supported decision-making is not yet legally recognised in the State of New York. Also, issues related to liability of the supporters were not yet defined.

The pilot projects shared a number of common goals as they all looked at ways to implement Article 12 CRPD. All the pilot projects had an intrinsic link with Article 19 and some clearly stated among their goals the realisation of it, even in countries where the link between guardianship and institutionalisation is frequently stressed. In this sense, pilot projects shared a common understanding that to end segregation and isolation, it is necessary to maintain and develop relationships to avoid dependence on one person and to utilise the environment of the person to build support, including support for decision-making.

In terms of activities realised, social work, training, awareness-raising as well as campaigning and policy work, drafting of legislation, and work with the media are common to most projects. In some projects, strategic litigation was included as one of the activities to work with individuals. The material produced by the project includes different sources: the most frequent are policy documents, legal analysis and draft laws, training material, practice guidance and templates developed by the pilot project staff, as well as other sample material for project participants (facilitators, supporters or decision-makers). To a lesser extent, project reports to donors, external evaluation reports and academic articles are available.

The next chapter analyses the pilot projects based on the areas and the questions of the framework developed in Chapter 4.

7 Findings From The Practical Implementation of Article 12 CRPD by Six Pilot Projects

Chapter 4 describes a proposed framework to ascertain how each pilot project presented in Chapter 6 implemented Article 12 in practice. The data from each of the pilot projects were analysed using this framework. The following chapter describes how this analysis was conducted and then presents the findings from this analysis using the nine domains of the framework.

As noted in chapter 6, Article 12 formed the philosophical foundation of the work in realising supported decision-making. The nine domains of the framework explored in the following sections looked at how the provisions and the theoretical concepts of Article 12 have been conceptualised and put in practice by the pilot projects through the process of extraction and analysis of data. Emergent findings are presented thematically for each for the framework's nine domains. Descriptions of inspiring practices from the pilot projects, which may be used and adapted by other projects in the future, are included in Annex No. 7.

7.1 Domain 1: Being a person before the law

Domain 1 considers how equality before the law for people with disabilities is conceptualised and described within the pilot study documentation and how the concept of personhood for people with cognitive disabilities is understood and which criteria did the pilot project use to define personhood.

Information relevant to this domain was limited, as no project explored or interpreted the concept of personhood. Only for two countries (Bulgaria and Colombia) did information exist that allowed exploration of either of the questions above. Sources of data are outlined below.

Bulgaria	BG_DOC_2	Policy document (legal aspects)
Colombia	CO_DOC_9	Law

In both countries, equality before the law was established in policy, with a presumption of capacity to de-link capacity from disability.

In Colombia, Article 6 of Law No. 1996 clearly states that "*All persons with disabilities are subject to law and have legal capacity on an equal basis with others without any distinction and independently of whether they use or do not use support for the realisation of legal acts. In no circumstances can the* *existence of a disability justify a restriction of legal capacity of a person.”* (CO_DOC_9). Legal capacity is clearly not based on, nor related to, disability or the use of support in exercising capacity.

In Bulgaria, policy development went somewhat further than declaring the presumption of capacity, taking into consideration that people with cognitive disabilities do not meet the traditional test of capacity (I understand the consequence of my action and I can express my will) and need other criteria to demonstrate and exercise their legal capacity. Bulgaria’s model included a lower threshold for people who do not meet the traditional test of capacity to enlarge the scope of legal capacity for people who do not meet this test (BG_DOC_2). A two-step test based on trusted relationship as a tool for expressing the will of the person with a disability has been designed: *1) The existence of a will/wishes of the person (presumption of capacity) and 2) The existence of at least one (trusted) person who knows the person and can give the best interpretation.* The second element can be demonstrated by four criteria for detecting the presence of trusted relationships: (1) voluntariness (reciprocity), both people trust each other, (2) Exclusion of undue influence: absence of history of manipulation, abuse and violence, (3) ability to interpret the will: existence of communication, stability of the relationship, (4) readiness to act in the interest of the supported person and to exercise his/her will most accurately (BG_DOC_2). These four criteria give verifiable and objective elements for a legal procedure, as they can be assessed by different sources.

With this two-step test, the Bulgarian model established verifiable criteria to guarantee equality before the law and attribute full legal capacity to people with cognitive disabilities.

7.2 Domain 2: Determination of support needs

Domain 2 considers how the pilot projects determined the person’s support needs. Specifically, the available information was analysed to ascertain:

- whether and how pilot projects conducted decision-making capability assessments
- what criteria pilot projects used to determine support needs and whether these criteria were disability neutral
- what tools and methods the pilot projects used to assess support needs
- who conducted the assessment of decision-making capability/support needs
- how the pilot projects involved the person in the choice of support level he/she requires

- whether and how pilot projects considered combining support needed for formal and informal decision-making assistance and how they assessed the need for formal decision-making
- if the pilot projects encountered people who refused support, what was their response

Data relevant to this domain was available for five projects (Bulgaria, Peru, Colombia, Czech Republic and New York) and includes primarily practice guidance and legal documents, as well as academic articles.

Peru	PE_DOC_1	External evaluation report
Bulgaria	BG_DOC_1	Practice guidance (including template)
	BG_DOC_2	Policy document (legal aspects)
	BG_DOC_5	Draft law
Colombia	CO_DOC_7	Policy document (including legal analysis and templates)
	CO_DOC_8	Academic article
	CO_DOC_9	Law
Czech Republic	CZ_DOC_3	Practice guidance (including instruments for individual work)
	CZ_DOC_6	Project material: sample legal document
New York	NY_DOC_3	Academic article
	NY_DOC_4	Practice guidance (template)
	NY_DOC_5	Practice guidance (template)

The emergent findings are organised under five topics: the key role of the facilitators; the tools used by facilitators to determine support needs; the participation of decision-makers in their support choices; the process of assessing support needs and how it fits within the system; and the specific areas for supported decision-making arrangements.

A key role in the process: the facilitator

The position of “facilitator” has been created in all the pilot projects, sometimes with a different name but with similar roles. The involvement and amount of work with each decision-maker performed by the facilitators have been different in each project but included several meetings with the decision-maker. Their role included:

- Identifying people from the network of each individual – who can act as supporters (in a legally binding agreement or informally) (PE_INT_1, CO_DOC_5, NY_DOC_4, CZ_DOC_3, BG_DOC_1)
- Identifying the areas of life in which support is needed (including communication support needs), (CO_DOC_5, NY_DOC_4, CZ_DOC_3, BG_DOC_1)
- Identifying goals to reach the person's life plan, and the steps to make it real (ZA_INT_1, PE_DOC_1, CZ_DOC_3)
- Drafting a supported decision-making agreement or an anti-crisis plan (CO_DOC_5, BG_DOC_1, NY_DOC_3, CZ_DOC_3)

The role of the facilitator included supporting a person to find out which person should support the decision-maker and in which areas. But facilitators did much more than that: they often had to do a comprehensive mapping of the person's relationships, skills and abilities, history, experiences or activities and interests and facilitate meetings with the decision-makers and their relatives.

In some projects, facilitators helped with a concrete goal or dream that people were asked to formulate as part of the project (like in Peru with the use of PATH, which stands for Planning Alternative Tomorrows for Hopes – a model of person-centred planning developed by John O'Brien, or individual plans in Zambia, in the Czech Republic, and in Bulgaria as part of the Step by Step programme).

Some pilot projects pursued a double goal: setting a support network and to activate decision-making processes with a concrete goal. This led to some tensions, especially in short-term projects, where the realisation of those plans has been really difficult: "*we find out is that even if they signed and committed to the work, there were a lot of difficulties with really doing what was included in the PATH plans*." (PE_INT_1). Support networks were left alone with realisation of PATH – with ambitious goals, without prior experience of working with this tool. Zambia also reported a lot of challenges in the realisation of the individual plans, sometimes also for legal reasons (legal barriers in the realisation of a goal) (ZA_INT_1).

Facilitator assessed the support needs of people with disabilities using diverse tools.

Tools and methods used to determine support needs

Facilitators used a range of different tools which included established measures such as the Supports Intensity Scale (AAIDD, 2015), as well as a range of tools that were developed specifically for the project.

Before assessing support needs, the facilitator needed first of all to know the person, as in most cases, the facilitator met the decision-maker for the first time during the project. Therefore, besides instruments to determine support needs, they also used a number of other instruments like Person-Centred Planning (hereinafter PCP) methods, or other tools for mapping communication and general skills and abilities to get to know the person before assessing his/her support needs**.** Person-centred tools ensured the participation of, and focused on, the decision-makers.

In Peru, the staff became acquainted with the project participants after their recruitment with three instruments: a questionnaire about the demographics and characteristics of participants, a self-determination scale and a scale of citizenship knowledge and then a fourth one has been added: a mapping of the skills and abilities of people with intellectual disabilities. The external evaluation states that it had been a challenge to find appropriate evaluation instruments as they do not exist in Peru. The instruments used in the project have been adapted from Spain and it required substantial work to make it accessible to people with intellectual disabilities (PE_DOC_1).

In Colombia, the project staff designed its own tools to do a preliminary mapping; this mapping is then used to develop a support system. The method for structuring a system of support contains 5 preliminary steps and then 2 more steps relate to the implementation of the support system (CO_DOC_7, CO_DOC_8):

1. Approach to the disabled person, his family and his social environment (space for dialogue)
2. Assessment of communication and support needs of the person and their family (PCP tools)
3. Identification of family and social support networks (Ecomapa)
4. Mapping of the community territorial offer and access routes to services which are relevant to facilitate decision-making and the realisation of the future plan (e.g.: services available...)
5. Preparation of a life plan and personal support plans based on people's wishes, interests and needs (information captured in an individual booklet)
6. Participation in training and information scenarios (meetings)
7. Implementation of follow-up actions (evaluation)

Similarly, the Czech pilot project mapped available support with PCP tools (in this case, the whole range of available PCP tools translated from the original tools by Helen Sanderson) and the Supports Intensity Scale (SIS), which both organisations implementing the project use on a daily basis with their clients, thus also in the framework of the project (CZ_DOC_3).

In New York, the pilot project staff created a specific tool, which provides four areas for specifying individualised decision support, which staff then refers to as the “Big Four” template (NY_DOC_4):

1. **Which** areas a decision-maker wants decision support in (i.e., financial matters, health care, living arrangements, etc.)
2. **Who** is chosen to provide that support (trusted persons in the decision-maker’s life)
3. **What** kinds of support (gathering information, helping to weigh alternatives or possible consequences, communicating decisions to others, etc.)
4. **How** support will be provided (face-to-face conversation with individual supporters for individual areas, group meetings, text, telephone, Skype, etc.)

A facilitation “Cheat Sheet” was also available to support the facilitator in discussing these four areas in detail (NY_DOC_5).

In Bulgaria, the evaluation of the person’s capacity for decision-making was set up with different instruments for people with intellectual and psychosocial disabilities. For the first group, a personal profile was prepared by the person himself supported by a facilitator. If necessary, a psychologist, a speech therapist, a person who had been working with or was otherwise close to the person with an intellectual disability and knew his/her habits, modes of communication and decision-making and expression of preferences had been included. The evaluation for people with psychosocial disabilities was done thanks to a questionnaire, including different situations in life (general information about the decision-maker and his/her environment; situations in life in which the person finds it difficult to make a decision; situations from the past in which the person found it difficult to make a decision; the attitudes of the person to these situations (does he/she find it is good to get support in this process); the person’s resources; the attitudes of the environment to these difficulties of the person in the process of decision-making; the resources of the environment; and how to get in touch with the decision-maker and people from his/her circle, whom he/she indicated (BG_DOC_1).

These five examples show that the pilot projects have worked with a wide range of instruments that are more or less complex. Mapping support needs, however, has been one element of a larger piece of work identifying the person’s characteristics, preferences and other information to find out more about the decision-maker. All projects have chosen a tool and practiced mapping of support needs. The different reports and interviews suggested that they have been successful in this activity. Giving a voice to people with disabilities has also been an essential aspect of the mapping exercise.

Participation of people with disabilities in their support choices

Identifying support needs implied, as a matter of principle, the participation of decision-makers in their support choices. The use of person-centred instruments and techniques described in the previous section could be a good indicator of the participation of people with disabilities in their support choices. However, in several projects, decision-makers have been asked for their views in meetings with their families and they did not always have the opportunity to meet a facilitator or a project staff member face to face. Therefore, the presence of other participants may have influenced the choices and preferences expressed by the decision-makers.

In Peru, the evaluation report states that people with intellectual disabilities have largely been involved in the choice of their support network. The evaluator mentions one case where the mother chose the support persons and three cases where they adjusted the choices made by their son or daughter, based on the justification that the selected persons were not available (PE_DOC_1).

In the Czech Republic, involving the decision-maker in designing his/her support plan and needs, working on the basis of the opinion and preferences of the person, was set as a priority for individual work. However, quite often differences of opinion and conflicts between the decision-maker and his/her family or guardian emerged. To take into account the daily-life reality of the decision-maker and the support provided by his/her relatives, the project staff used the PCP tool “what is important to / what is important for” to work on those differences of opinions and make relatives more aware of their own fears about security and well-being. It often helped to find the right balance between the fears of the supporters and the claim for autonomy by the decision-maker and helped to adjust the appropriate amount of support (CZ_DOC_3).

In New York, the project staff worked exclusively with the decision-makers in the preparation phase and supporters were invited at a later stage. Family members reported being concerned and uncertain about their roles. This was the starting point for project staff to think about a mediation model and the need for mediation processes to resolve competing perspectives of supporters (NY_DOC_3).

This domain also aimed to consider data concerning, and the experience of, people who refuse support. No such information was found in the projects’ documentation. One obvious explanation may be that people have usually voluntarily signed up for the pilot projects. On the other hand, pilot projects report about participants dropping out (see the detailed description where available in Project participants Chapter 6). The reasons are not known but it cannot be excluded that some decision-makers did not want to have their support organised as planned by the pilot projects.

Beyond the piloting phase, projects have developed ideas on how to make support needs assessment sustainable at a system level.

Support needs assessment as a component of the new system

Pilot projects have assessed their participants as part of the project activities, but they have also considered and planned how such an assessment would fit as an element of the system, in their countries, beyond the pilot.

In Colombia for example, the evaluation of the support needs has been planned to be realised by a facilitator, a new position created in several public or private institutions. The idea was to create a new service, which would be available free of charge in all the districts of the country (Article 11 of the Colombian legislation, CO_DOC_9). The law suggests a list of institutions where facilitators could be employed, but this list is not exhaustive, which gives the possibility to expand the number of such institutions. The facilitator’s work should be done in line with guidelines and protocols to be developed in partnership with organisations of people with disabilities and disabled persons themselves (Article 12, CO_DOC_9).

Two mechanisms are possible for the recognition of support agreement: the agreement is certified by a notary or a mediator or by a court proceeding for the attribution of formal support measures. But in both cases, an assessment by a facilitator in one the institutions should be provided.

If there is a court procedure, a judge will certify the attribution of formal support to a person with a disability. The judge, in this case, must follow the conclusion of the facilitator’s report. This means that the judge cannot extend the areas of support for the realisation of legal acts which have not been asked for in the proceedings. The judge has to stick to the areas identified during the assessment. In addition, the judge should include in the judgment other support measures, such as support programmes for families, which are necessary to ensure autonomy and respect of the will and preferences of the person, identified in the report done by the facilitator (CO_DOC_9).

The Colombian law requires that the person participates in the judicial proceeding (with one exception); otherwise, there is a risk of invalidating the procedure (CO_DOC_9).

The Bulgarian model of support needs assessment was designed in a different manner. The principle is that people exercise their legal capacity independently. When a person does not pass the traditional capacity test, appropriated measures to enable the person to exercise his/her legal capacity should be introduced (in an out-of-court procedure or in a judicial proceeding depending on the situation). Support measures can be provided to an adult person who, as a result of an intellectual disability, mental disorder or dementia has serious difficulties in understanding the essence of his/her decisions and the consequences thereof when carrying out specific legal actions. This guarantees a specific right of support in the exercise of legal capacity to people with disabilities, without losing their legal capacity (BG_DOC_1, BG_DOC_5). Seven principles, designed according the UNCRPD, underpin the mechanism for determination of support measures: 1. necessity and sufficiency; 2. respect for the wishes, preferences and values of the person (loved ones in case there is no possibility to determine wishes and preferences); 3. proportionality (only in areas where support is needed); 4. duration (limitation in time); 5. avoidance of conflict of interests and undue influence; 6. flexibility of the measure (changes should be possible as the person’s skills and experience evolve) and 7. participation of the person. It explicitly excludes medical or psychiatric assessment (BG_DOC_2).

In the event of an out-of-court procedure, the contract for supported decision-making signed between the decision-makers and the supporter(s) includes specific areas for which supported decision-making will apply, based on common agreement and trust.

In the event of court proceedings, the assessment of support needs should be carried out by a multidisciplinary team including speech therapist, social worker, psychologist, psychiatrist and other specialists, if necessary. The team should also include a close relative or a person who works closely with the decision-maker (a person who knows about the habits, communication, routine and preferences of the person).

Both countries have envisaged out-of-court and court procedures for the recognition of a supported decision-making agreement but the formal assessment of a person’s support needs is organised differently (one facilitator versus a team) and at different stages of the procedure (at the beginning of the process versus once there is a court hearing).

Specific areas for supported decision-making arrangements

A key challenge identified from the analysis of the pilot projects is the issue of the overlap between day-to-day support and support for decision-making.

All pilot projects organised support for both informal (day-to-day) and formal decisions. Pilot projects did not draw any distinction between day-to-day decisions and legal acts. As for example in Peru: about clothing, household activities like cleaning, cooking, privacy, friendship and social life and included some formal decisions, moving around and the use of public transportation, signature and ID card, money management and work (PE_DOC_1).

The pilot projects have described formal support needs in documents which correspond to a supported decision agreement between the decision-maker and the supporter. Often the agreement was legally binding, in the sense that the parties were obliged to keep to the agreement but not in all the pilot projects[87].

The result is that agreements on supported decision-making are simple and flexible (CZ_DOC_6, NY_DOC_5. BG_DOC_1, CO_DOC_7), thus being comprehensible for its parties, by setting up who is/are the supporter(s) and how supporters can help the decision-maker in taking decisions. They do not include details about decision processes – just how the decision-maker wants to be supported. This avoids entering into complicated descriptions and it keeps the complexity of decision-making processes outside of the agreement. Supporters provide support for both day-to-day and formal decisions. To perform, modify or terminate a legal act, the person acts as a decision-maker with the person(s) designated as supporter, in the way that is described in the agreement – the agreement between the supporter(s) and the decision-maker is needed to guarantee this process of performing, terminating or modifying a legal act. Day-to-day decisions may follow the same process, although the agreement may be needed only for legal act. It reflects the position that the exercise of legal capacity is not limited to *legal acts* only but may include a more general *right to decide*, covering both day-to-day decisions and legal acts. What is outside of the agreement belongs automatically to the informal support.

An important and practical result of the process of setting up support networks by the pilot projects, is that the decision-maker knows he/she can turn to one or more persons of his/her circle of support when dealing with specific issues – most of the activities will remain informal depending on the level of autonomy of the person (e.g.: around money management: preparing a budget, looking at prices of different things).

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[87] Not all the projects developed agreements and the New York project did not share the sample agreements.

Adding to that, the staff of the pilot project in New York overcome the dichotomy between day-to-day support and support for decision-making and talk about **unpacking decision processes**: *"facilitating a decision-maker in thinking about, and answering the questions about support in decision-making is, it turns out, also teaching decision-making: what information do I need to decide on clothing today, what help, etc."* (NY_DOC_3).

Through the mapping of skills, of supporters, of preferences and wishes of people with disabilities involved in the projects, the project staff could respond to all the elements that are important in, and form the essence of, the life of each individual. The Colombian collective group of authors described this process as follows: *"The evaluation of personal competences measures the ability to perform a task, the achievement of objectives depends on individual competence. On the contrary, the evaluation of supports detects points that can be reinforced, provides resources and strategies to promote development, education, interests and personal well-being. A person's support needs differ both quantitatively (in number) and qualitatively (in nature). The intensity of the supports depends on the situation, the context and the particular needs of each person at a given moment"* (CO_DOC_8). Simple agreements and chosen supporters guarantee the accessibility of the process of decision-making for people with intellectual disabilities.

The next section explores the availability of supports for decision-making of different types and nature.

7.3 Domain 3: Available supports

Domain 3 considers what support for decision-making was available or provided, including:

- what support for decision making was made available/offered by the pilot project
- what tools and measures were used
- how these respected people's will and preferences and human rights
- how projects conceptualised and used a panel or circle of support to support people in exercising their legal capacity
- what types of decisions were supported, e.g. was support available for voting, in financial affairs, in housing, in health care decisions, in personal life decisions (such as work, relationships, leisure time activities, holidays), to enter a contract?

- and if pilot projects dealt with freedom of contract for people with cognitive disabilities, including contracting supported decision-making agreement

The section draws on data from all six projects (Bulgaria, Colombia, Czech Republic, New York, Peru and Zambia) and it includes interviews, academic articles, evaluation reports, policy documents, practice guidance and project training material, project legal documents as well as easy-to-read materials, as the following table summarises:

Peru	PE_INT_1	Interview with project staff
	PE_DOC_1	External evaluation report
Bulgaria	BG_DOC_1	Practice guidance (including template)
	BG_DOC_2	Policy document (legal aspects)
Colombia	CO_DOC_5	Project material: online training course
	CO_DOC_7	Policy document (including legal analysis and templates)
	CO_DOC_8	Academic article
Czech Republic	CZ_DOC_3	Practice guidance (including instruments for individual work)
	CZ_DOC_4	Evaluation of the experiences of participants in using decision-making instruments
	CZ_DOC_8	Practice guidance (for supporters)
	CZ_DOC_9	Project material: sample legal document (trust fund contract)
	CZ_DOC_10	Project material: sample legal document (three-party agreement with bank, client, and supporter(s))
	CZ_DOC_11	Project material: easy-to-read information material about banking
Zambia	ZA_INT_1	Interview with project staff
New York	NY_DOC_3	Academic article
	NY_DOC_4	Practice guidance (template)

The findings explore how the pilot projects embraced a holistic approach to support; how they designed a support system based on wishes and preferences and how they have featured support in specific areas, especially in the area of finances and assets.

A holistic approach to support

By embracing a holistic approach in the broad sense of its definition in Article 12 CRPD, pilot projects focus on support to exercise legal capacity and on support in general, as described in the previous section. The pilot projects demonstrated that one cannot envisage legal capacity without informal support, including day-to-day decisions and support for the exercise of legal capacity. Aware of that complexity, the pilot projects have included both in a broader system where informal and formal supports are interlinked and interdependent.

The Bulgarian model, for this purpose, defined two categories of support (BG_DOC_1), which are complementary and subsidiary, and proposed a panel of support measures in both categories:

- "Support in the process of decision making" is the informal help which people use constantly in their life – for example, consulting with friends and acquaintances on various issues. The model included the following informal forms of support in this category:
    1. support groups of equals (peer support)
    2. consultation with a trained specialist (expert advice)
    3. social service (decision-making skills (re)-training and social support)
    4. mentor (personal advisor) to help the person cope with the exercise of his/her rights.

  Through these four instruments, the person is able to learn and relearn some of the skills for decision making. Decisions are taken by the person himself/herself. *When necessary,* more instruments can be used in parallel for people who need more support (BG_DOC_1, BG_DOC_2)

- "Supported decision-making" is a process that has important legal consequences. The chosen support measures should help the decision-maker in planning his/her future life in the community and making decisions about his/her personal life, health and finance or property.
  Supported decision-making includes a range of measures aiming to provide the necessary support for independent exercise of rights (performance of legal actions and/or inaction) in order for certain

consequences to arise based on the will and preferences of the supported person. The model includes the following measures:

1. preliminary measures (preliminary injunctions and long-term power of attorneys)
2. contract for supported decision-making (signed by both parties based on their will or as a result of a special judicial procedure)
3. joint decision making
4. facilitation (crisis facilitation). (BG_DOC_1, BG_DOC_2)

The proposed support measures of both categories can work *individually* depending on the need for support and the wishes of the person and *in combination*. For example, a decision-maker may use support from a group of equals (peer support group) and may have an anti-crisis plan, if a facilitation measure needs to be activated in case of crisis.

In the Czech Republic, this holistic approach is embedded thanks to the identification of 5 key aspects of the "support system" (CZ_DOC_3):

1. Assistance with understanding and expression (including non-verbal communication, total communication principle, two-way communication)
2. Building and strengthening networks of personal relationships (also for people with no trusted relationships)
3. Future planning (for bigger decisions and changes in life)
4. Creation of a support plan (The support plan can be focused on different areas, have different content – as needed. By default, however, it should contain clear information on what the support should look like, with what frequency / under what circumstances and to what extent the support is provided and who provides the support.)
5. Formal support (legally recognised instrument)
6. Technical support to implement a decision (administrative and practical aspects of a decision, e.g.: making a payment online, etc.)

The Czech and the Bulgarian models attempted to include a range of support measures and gave the foundations for a system of supported decision-making. The pilot projects have set up, thanks to these support measures, individual plans and offered concrete activities to make support to exercise legal capacity a reality, as explored in the next section.

Designing a support system based on wishes and preferences

All the pilot projects have worked on the basis of the wishes and preferences of their participants, putting an end to the criterion of "best" interest of individuals. The claim of the pilot projects is that support needs should be based on the wishes and preferences of individuals, without exception, including even those with high support needs.

The selection of appropriate measure of supported decision must be consistent with the personal characteristics of the person and his/her preferences – for example, some people do not want the support of a group but prefer to use the support of a personal advisor (BG_DOC_1).

The following example from the New York pilot project illustrates the primary consideration of wishes and preferences: "*decision-makers have come up with areas for support (e.g., "support for bi-romantic, non-sexual relationships," "career and professional development as an advocate," "education as a life-long learner"), or particular kinds of support (e.g., "[h]elp [to] create the space for me to communicate my ideas and decisions to others [because t]here are times when I need assistance to speak in a group or meeting") that had never occurred to anyone in the project, but that faithfully convey where, and in what ways the decision-maker wishes support"* (NY_DOC_3).

The pilot projects have not only provided space for wishes and preferences about support, but they have also given the opportunity for people with disabilities to express their dreams and their goals, sometimes for the first time in their lives: "*people are able to come up with (…) what their dreams are, what they aspire to do in the future*. (…) *And also the families, their supporters ensure that they implement that plan according to the desires of the individuals, unlike substituting their decisions with theirs or with somebody else's*" (ZA_INT_1).

How to support people with disabilities in specific and complex areas of life, such as health care, finances and assets has also been explored by the pilot projects.

Exploring features for specific life areas (finances, health care and contracts)

Finance is an area of life that raises particular concern and has been treated as a specific issue in different projects, thanks to the initial work and research on alternative models in financial affairs undertaken by the Israeli organisation Bizchut[88], a reference quoted by the pilots (CZ_DOC_9/10/11, CO_DOC_7).

In some countries, the area of finances is linked with discriminatory practices for people with disabilities, as shown in Zambia: "*you find that in the communities people with intellectual and psychosocial disabilities are not allowed to run their own affairs, […]. For instance, there are some people who would love maybe to own land, there are some people who would love maybe to*

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[88] See the report by Yotam Tolub, BIZCHUT, Alternatives to Guardianship in financial affairs (Apr. 3, 2016), available at http://bizchut.org.il/en/573 (last accessed 27/10/2021).

get loans from the banks, maybe to start businesses, but they cannot be allowed because of their condition, which is also supported by the laws of Zambia. I talk about the Insurance Act, the Rules and Administration Act which does not allow them to maybe inherit property and it states clearly that they cannot run their own affairs. (…) they've been somehow promoting this informal guardianship you know". (ZA_INT_1) The organisations have made recommendations in terms of legal reforms to abolish these discriminatory practices.

To tackle this knotty issue, in Colombia pilot project partners have undertaken research identifying nine mainstream instruments existing in the legal system, which they describe in a simple language to explain their advantages and disadvantages and how they can be used in favour of / with people with disabilities and support them with money and asset management (CO_DOC_7). Similarly in the Czech Republic, several activities have been dedicated to the accessibility of financial issues: piloting trust funds agreement, a new legal instrument available in the Civil Code since 2014 (CZ_DOC_9) and negotiating with banks and the Czech Bank Association several ways to accommodate the needs of people with disabilities (easy-to-read manuals, tripartite contract between the bank, the person and the supporter, see CZ_DOC_11). In addition, some people have required limits for themselves, in the process of identifying support needs, because they know they can behave in a way that damages them. For better protection and less stress, they organised their own limitations, as this person reports: *"That's why I left him my card. As I have a card, I pay, I pay, I pay, and then I don't have money, for example, and I've dealt with this once with my supporter. So we agreed that he has the card with him and I'm glad I don't have any problem. Otherwise I can't sleep because of this" (Saša)* (CZ_DOC_4).

Health care is the second area to which pilot projects have dedicated special attention. The possibility to provide guidance for medical and health-care decisions in the event the person becomes incompetent to make such decisions or to appoint someone to make health-care decisions on a person's behalf (sometimes known as advance health-care directive or health care proxy) is available in different jurisdictions. Therefore this instrument has been included as one potential measure/tool in a future system of support and has been used sometimes as an additional instrument to supported decision-making agreements for some project participants (Czech Republic, Colombia, New York). The Bulgarian model developed a tool called an "anti-crisis plan", including an agreement on the process of decision-making during crisis. The plan contains what the person considers the most important to him/her and describes his/her desires and preferences while he/she would be in a crisis when he/she may act differently. The person can also decide to limit his/her autonomy by giving power to selected trustee(s), and the range of issues on which they can make decisions. The plan also includes when and how power is restored to the person (BG_DOC_1).

This framework domain aimed to look at freedom of contract. No information could be found in the analysis of documentation. The issue of contracting is very complex and was therefore probably not dealt with by the pilot projects.

7.4 Domain 4: The role of supporters: duties and liabilities

Domain 4 considered how their duties have been explained to supporters (such as training/guidelines/guidance material) and for which group of supporters this material was designed (family members and friends and other groups of people). It also enquires about potential new supporters, how they have been reached out and what methods or techniques were used to create support networks. This domain also looked at how pilot projects conceptualised liability, including whether guidelines to protect supporters from liability were developed and tested.

Available information was found in documentation from all the six projects (Bulgaria, Colombia, Czech Republic, New York, Peru and Zambia). The data sources included mainly interviews as well as practice guidance materials as follows:

Peru	PE_DOC_1	External evaluation report
Bulgaria	BG_INT_1	Interview with project staff
	BG_DOC_1	Practice guidance (including template)
	BG_DOC_2	Policy document (legal aspects)
Colombia	CO_INT_1	Interview with project staff
	CO_DOC_9	Law
Czech Republic	CZ_INT_1	Interview with project staff
	CZ_DOC_3	Practice guidance (including instruments for individual work)
	CZ_DOC_6	Project material: sample legal document (supported-decision agreement)

	CZ_DOC_8	Practice guidance (for supporters)
Zambia	ZA_INT_1	Interview with project staff
New York	NY_DOC_3	Academic article

The findings explore who are the supporters, persons from existing networks and newly involved persons (section 1) and how they have been trained to perform their new role (section 2).

Existing and new supporters: creating a support network

From the documentation and the interviews, this is the area where the projects have been most productive and at the same time where they present differences in the way their activities have been realised. In the New York and Peruvian projects, the pilots have worked only with existing networks. In Zambia, people have successfully chosen several supporters, usually from the family but also from the community. People with intellectual disabilities have often chosen parents and siblings, while people with psychosocial disabilities have chosen their peers, some close friends and also the social workers who are close to them in the community, their partners and also the pastor from the church they go to (ZA_INT_1). In Bulgaria, Colombia and in the Czech Republic, the staff worked with existing supporters but also looked at expanding the network with other people from the community, combining what the project defined as natural supports (family, relatives or staff) and community resources, people who are not related to the person with disabilities.

In the Czech Republic, pilot staff members' own networks were activated, asking people they know, mapping local resources – local groups, local activities to get involved in, etc. and together they have made plans to ensure that people would be fully participating – truly contributing to the community activities (CZ_DOC_3). In Colombia, where all the project participants live with their families, in addition to the mapping of relations, they used another instrument called "Ecomapa" (see its presentation in 6.2.2) to reinforce or enlarge support networks. "*While the relationship map allows to identify the support network with people, the "Ecomapa" allows to identify the support network such as organisations and institutions. That helps more to identify community support. (…) A mapping of what is close to me, what is in my place, where I live, what is around where I live and what can help me in certain situations. We identify that the organisations of people with disabilities themselves are a potential support network for people and families. And we started to look at the map, who is in it, and who can work for me as a support network and so we begin with them to build that support network by observing* *and looking at the whole context, both family and social/community."* (CO_INT_1). Families who met in the context of the pilot projects also started to form a support network among themselves, such as for example, one mother helping another boy with basic education skills, thus creating friendship and support between two families (CO_INT_1).

While the Colombian pilot project did not include people who had no trusted relationship, they have included a mechanism for these people in the law. Article 14 of the law 1996 establishes the possibility to designate a Personal Ombudsman for people who have no trusted relationship – the ombudsman can be designated by the judge to provide the support needed for the realisation of the legal acts of the right holder (CO_DOC_9).

Creating networks for people who have no trusted relationship was tested in practice in the Czech Republic and Bulgaria because many people with intellectual and psychosocial disabilities have been placed in institutions and therefore have no trusted relationship.

In the Czech Republic, in most cases, this was done through hobbies or other leisure time interest and connection, as in Hana's example based on her music interest: "*Hana's dream was to meet people, to have someone around whom she could talk about anything. We therefore started to expand Hana's network of relationships. So we tried to find opportunities where she could regularly participate in activities in a mainstream environment and where she could establish new friendships with people outside the institution. For basic orientation, where to start looking for new relationships for Hana, we created a so-called rich picture together. (…) Hana returned in her memories to various experiences, from which the social worker made notes and pasted them around Hana's picture. During a later meeting, the rich picture showed that Hana enjoys singing and music. When this became clear, we could start looking for people with whom Hana could share her interest in music. Because Hana has no personal ties in the city, other than social service professionals, I used the network of my personal friends and acquaintances. I went through my contacts and found two acquaintances who lead a choir. One of them was the first to agree to try it, even though he was a little afraid. Thanks to this, Hana started to go to the rehearsal of a choir of students and former students of a higher vocational school once a week, she also sang at a Christmas concert and at a garden party"* (CZ_DOC_3).

For some people, the first step before expanding the support network has been to create a communication profile, so that the person would be understood by a range of other people, not just by one or two very familiar people (CZ_DOC_3).

In Bulgaria, it was also the project facilitator's role to gradually expand networks (often composed only of family and staff) by involving other people. Two mechanisms have been used: volunteers for people with intellectual disabilities and support network groups for people with psychosocial disabilities (BG_DOC_1). Bringing new people into a circle has been a challenge: the pilot coordinator in Bulgaria reflects on it, especially for people with intellectual disabilities: *“slowly the family supporters step back to more people from the communities. (…) it was a long process to show them that if those people have some supporters who are not belonging to the family network, it's not creating risks to these people”* (BG_INT_1).

In one of the places where the pilot has been implemented, the project facilitators tried to create relationships in an environment where there was no relationship other than with paid staff. The experience was especially challenging, as it involved people who were just placed in small group homes after a children’s institution was closed down. “*So most of them were really not communicating at all, without any kind of relatives and close people; they were absolutely (new) to the environment. I saw that of course they started from a very basic social level. They helped them to make a small social decision in everyday life: to choose to stay here or to be in another room and choose to decide to go outside or to stay in. And I saw how they started, first their task was really to teach them how to make choices. They were in a very high dependency to care. I think it was very successful. They built trusted relationships. (…) I saw slowly, of course not with all the people in this facility. They took two or three cases that they can manage. And I saw how slowly this started to develop and to open and build social relationship and helped those people to build social relationships”* (BG_INT_1).

In the Czech Republic, to compensate for the lack of support persons and volunteers available, some supported decision-making agreements have been created by combining supporters from the family circles and from services (not with individual staff members but with organisations as legal entities for practical reasons and for liability). Two conditions should be reunited to combine social service and family members as supporters: staff from a social service plays an important role in the life of an individual and they have been chosen as supporters by the decision-maker, and family or relatives are physically far away. Specific safeguards, to avoid any conflict of interest, have been included in the agreement. Including service staff in the supported decision-making circle may be debatable because of the numerous conflicts of interests and dilemma between personal and professional views. This model, however, gives the chance to decision-makers who have few supporters and who are far away from their relatives to benefit from a supported decision-making agreement (CZ_INT_1 and CZ_DOC_6).

In addition to the selection and the identification of support persons, the pilot projects have trained and prepared supporters for their new role.

Training and education of supporters: understanding a new role

All pilot projects included an educational or training part and/or for family members and other supporters. They have taken different forms: online courses, in-person training or information sessions, written material and videos. The content also varied a lot from basic awareness raising and information to detailed practice guidance material.

In Peru, workshops were held every two weeks over 8 sessions with the main carers in both pilot places focusing on a large panel of issues: rights, independence, autonomy, decision-making and the future of PID, as well as guardianship and sexuality (PE_DOC_1).

Education and awareness-raising for supporters and families happened as well throughout the process in Colombia. The person was at the centre of the process, maybe leading some meetings or planning session or just having the possibility to express his or her own views. The facilitator's role has often been focused on keeping the person at the centre. His/her role is to help families and friends to understand what is the role of the supporter and what is the role of the decision-maker, and that the decision-maker is the one who's will and ideas should be respected and followed (CO_INT_1, CZ_INT_1).

In the case of the New York pilot, a "Supporters' Guide" will be drafted in year five of the project, drawing on newer empirical research and proposals, and grounded in the experiences of supporters and, importantly, decision-makers, in their own pilot (NY_DOC_3). This material will be written based on the pilot project experience – therefore it will be interesting to compare the content with the material developed by other projects, where the material has been written at the beginning of the pilot.

In Bulgaria, they have reached a total of four training programmes about supported decision-making with a range of training and methodological materials: for facilitators of supported decision-making, for professionals from social services, for people with intellectual disabilities, for parents and for self-advocates, each divided in different modules. The project leader commented that "*the best trainers are sent to the parents group. Because it's really the most challenging one*" (BG_INT_1).

Besides information sessions and trainings, several projects have worked on a description of the rights and obligations of the supporters. The provisions suggested by different pilots are quite similar; the supported person being the decision-maker, the supporter can be liable only where he/she would have obviously violated or not fulfilled the obligations contained in the agreement with the support person.

The Bulgarian model, for example, includes the following obligations of the supporter:

1) The obligation to study the true preferences and desires of the supported person
2) The obligation to actively gather information about the relevant decision
3) The obligation to respond to a risk of interest infringement by initiating a procedure for changing the measure
4) The obligation to act in good faith and with due diligence
5) The obligation to initiate the procedure for changing the measure when the fiduciary relationship is broken down. The fulfilment of this obligation relieves the supporter of responsibility
6) The right to terminate the contract unilaterally.

The supporter is liable for any damages or foregone benefits (owes compensation) if they are the result of failure to fulfil the obligations under the contract. In case of dispute or disagreement, the supporter will be liable if he/she does not fulfil the following obligations: 1) initiate legal proceedings to review the status of the supported person and 2) send a notice of termination of the contract to the register. If there is no failure of these obligations, the supporter is relieved from liability and bears no objective responsibility (BG_DOC_2).

In Colombia, article 50 of the law 1996 states that the responsibilities of the support person will be personal only if he/she acted in contradiction with the terms of this law, other civil and commercial laws of Colombia or if he/she has obviously violated the terms of the agreement of support, of the advance directive or the judgement about support, and because of this, he/she has caused damages to the right's holder or against a third party. The support person will never be responsible for personal damages or financial damages of the decision-maker when they acted in conformity with the will and preferences of the decision-maker (CO_DOC_5).

In the Czech Republic, the law does not include any provision about liability of the supporter. A set of ethical and practical guidelines have been drafted by the project staff, in consultation with a large group of experienced supporters, based on their practical experience. This practice guidance describes the ideal attitudes supporters should adopt, good practice in reflecting about supporters' work as well as advice about what to do in case of conflicting opinions, to avoid liability (CZ_DOC_8).

The next section explores the process of supported decision-making: how supporters and decision-makers collaborate and how will and preferences of the person are key in this process.

7.5 Domain 5: Supported decision-making processes

Domain 5 considered what mechanisms for decision-making (such as methodological guidelines, facilitators for supported decision-making) were used and how those respect the rights, the will and preferences of the decision-maker; and how they were monitored (monitoring both the decision-making process and the result or either); including whether decisions were recorded, and whether guidelines for recording have been developed (to build a history of decisions and track supported decisions).

This domain also aimed to study:

- how did pilot projects seek to clarify the difference between best interests' decisions and best interpretation of the will and preferences
- whether projects have been confronted situations where the will or preferences of the decision-makers are unclear, conflicting or absent and what guidelines have been developed and tested to support the decision-making process
- whether pilot projects have been confronted with emergency situations or situations of serious adverse effect and how they did respond
- and finally how they assessed risks, and whether they tested risk assessment plans.

Relevant data have been found in material from all the six pilot projects (Bulgaria, Colombia, Czech Republic, New York, Peru and Zambia). The data sources come from practice guidance and varied materials as follow:

Peru	PE_INT_1	Interview with project staff
	PE_DOC_1	External evaluation report
Bulgaria	BG_DOC_1	Practice guidance (including template)
	BG_DOC_2	Policy document (legal aspects)

Colombia	CO_DOC_1	Project report to donor
	CO_DOC_2	Project report to donor
	CO_DOC_3	Project report to donor
	CO_DOC_4	Project report to donor
	CO_DOC_9	Law
Czech Republic	CZ_INT_1	Interview with project staff
	CZ_DOC_3	Practice guidance (including instruments for individual work)
	CZ_DOC_4	Evaluation of the experiences of participants in using decision-making instruments
Zambia	ZA_INT_1	Interview with project staff
New York	NY_DOC_1	Evaluation report by external evaluator
	NY_DOC_2	Academic article
	NY_DOC_3	Academic article

The findings present the role of facilitators in reporting and monitoring supported decisions, the practical guidance pilot projects have described for situations where will and preferences are absent, unclear or conflicting and how they have interpreted and put into practice the notion of dignity of risk.

Reporting and monitoring supported decisions

As described above, facilitators played an important role in determining support needs, in identifying supporters, but also in facilitating meetings with the supporters. But their role included even more tasks: they helped in securing support (e.g., what can be done to help with money management), guiding supported- decision processes or facilitating the achievement of one decision or of a long-term goal. Thus, they often helped the person execute the decision.

Because of the intense and varied tasks facilitators had to perform, recording of decisions and techniques to reach decisions has not been the focus of the pilot projects, although some instruments have been used and are available. Where the work of the pilot project was only to set up the supported-decision agreement, no systematic feedback about how it worked in practice is available. There may be an evaluation of the participants at the beginning of the project and then another one at the end of the project, as it was done in Peru, (PE_INT_1), but no regular record or note taking has been organised.

All the projects have files relating to the project participants, which are kept by the facilitator or authorised staff (PE_DOC_1, ZA_INT_1, BG_DOC_1). In Colombia, the files are compiled in the format of a field journal (*diario de campo*), which gives a lot of details about the person's activities and decisions (CO_DOC_1 to CO_DOC_4). The project staff made efforts to provide unified and systematic information reporting guidelines based on observation and notes from conversation with decision-makers by fieldworkers.

The Bulgarian project has created a tool for decision-making as a simple method, which puts the person at the centre of the process and gives a structure to proceed for a decision with the involvement of a support network (step to form a decision) – see the inspiring practice in Annex No. 7 (BG_DOC_1).

In the New York pilot, the situation at the end of 2019 is that the project staff only start to receive information about how decision-makers are using their agreement through support group meetings they are holding (NY_DOC_3). The staff planned to use support group meetings further to see how decisions are made with support agreements.

In the Czech Republic, to gather missing information about how decisions are made in practice for project participants, once they had their agreement, a small qualitative analysis among those participants was conducted to get feedback on how support is working in practice. Where possible, both the person and his/her supporter(s) have been interviewed, but in some cases only the supporter(s) have been interviewed (CZ_DOC_4). The analysis provided several positive points, especially on financial independence:

- Greater independence of the decision-maker, especially in deciding on their finances (in the way and frequency of using money), on their health, employment or housing
- Involvement of the decision-maker from the beginning in the whole process, i.e. from court proceedings to, for example, the opening of a bank account. Within it, the decision-maker gains experience, insight and understanding of what needs to be done.
- Overall, more freedom in setting up mutual cooperation, which is based on mutual trust

The negative aspects identified by the analysis relate to the multiple roles of supporters (as parent and support, social worker and supporter) and uncertainty on how to deal with conflicts in (trusted) relationships.

To sum up, some sort of reporting is taking place in all the projects, but it is difficult to determine the level of detail and the quality of the reporting, as the material is often not available (because of personal data protection).

The staff of the New York pilot reflected on the role of the facilitator and its evolution as follows: “Trainings now stress that facilitators are not decision supporters; their role is to assist decision-makers to make decisions with the kinds of support they desire. Training now directs the facilitator to reflect on the decision-making processes rather than engage in directly supporting decision-makers to make decisions about their lives” (NY_DOC_1).

The next sub-section looks at the specific situations where will and preferences are absent, unclear or conflicting.

Situations where will and preferences are absent, unclear or conflicting

The pilot projects have explored and produced practice guidance for situations where will and preferences are absent, unclear or conflicting. These models have been described by the pilot project staff on the basis of their real experience during the project and in anticipation of such situations. However, it is not known how often this arose in practice.

The Czech model attempts to define levels of decision-making, in the practical guidance for individual work (CZ_DOC_3). Three levels have been distinguished: the autonomous decision-making level (that is to say, I can make my decision on my own without formal support), own decision-making with support (support is intentionally arranged but the individual can clearly express his/her will and preferences). The third level is defined as follows:

Decision-making based on the best possible understanding of a person's will and preferences: the circle of support (based on trusted relationships, people who know the decision-maker intimately), plays an important role: the task of its members is to interpret the will and identify preferences of a decision-maker on the basis of a detailed understanding of his preferences, behaviour and personal history. Thanks to such an understanding, supporters may be able to give an interpretation of a person's will to a third party, including situations where legal action is required. Decision-making based on the best understanding of a person's will and preferences must be the last resort (CZ_DOC_3).

In its range of supported decision-making measures, as presented in 6.2.3 the Bulgarian model included a “crisis facilitation” measure, to be used in emergency situations. In order to proceed with the crisis facilitation at least one of the following prerequisites must be present: a) there is an obvious risk of serious loss of property or an imminent risk of serious or irreversible harm to the person or their relatives; or b) the person expresses preferences at some point, but these preferences are in conflict with his/her previous expression of will. The procedure includes the appointment of a facilitator, for a short period (no more than 6 months/1 year) through a judicial proceeding. The facilitator, thanks to the court decision, can establish and monitor an individual council, composed of close people. The individual council then makes concrete decisions based on the persons' past and present wishes, values, will and preferences as well as the current circumstances the person is facing (e.g., treatment). The facilitator monitors the efforts of the council to listen and involve the person, and can approach the court, if necessary. This measure can be initiated only after all possibilities for instituting measures for support decision making have been exhausted. It is also limited to a specific range of decisions and any person with a legitimate interest can be part of the council (including non-governmental organisations) (BG_DOC_3).

The last section looks at the way pilot projects have put in practice the concept of "dignity of risk" in supported decision-making processes.

The dignity of risk

Taking risks is an important aspect of educational and awareness raising activities of the pilot projects, especially towards families. All the projects have dealt with this issue, by identifying and evaluating risks as well as encouraging progressive risk taking.

In the New York pilot, the information sessions included advice about practicing decisions, as the project staff believe that practice leads to increased skill, and that cultivating relationships will make decision-makers less vulnerable to abuse, neglect, and exploitation. "*Rather than focus on proving that SDM makes decision-makers less vulnerable to certain risks, SDMNY has endeavoured to convince those it has reached that SDM makes decision-makers better equipped to face and avoid those inevitable risks,*" says the staff (NY_DOC_1). Facilitators helped supporters and decision-makers to consider risk in the process of decision-making.

In Peru, from the interviews with project participants and their families, two key life areas have emerged when talking about risk taking: the use of public transportation and the issues related to future plans (e.g.: having a partner and a family life). Fears from families have been compared before and after the project, and the evolution of their positions showed that accepting risk is parallel with the empowerment process and the understanding that people with intellectual disabilities need to be experienced to face the reality and potential dangers. The evaluation report demonstrated that over 18 months more than half of the participants increased their abilities to move around; they improved their skills in using public transportation or just walking alone for a short distance from home. Two people also learned how to cross the street. However, families reported that they had received no support in this process. They had to invent a step-by-step method. It is clear though that the project stimulated these efforts. On the other hand, on the topic of having a partner and a family life, families and carers did not really change their views. Very few would actively support them in building a relationship with a partner. For example, being in love would not include a normal adult sexual life. Due to the short life of the project there was not enough time to consider these issues and to educate families to work with risk taking and to build experience (PE_DOC_1).

In the Czech Republic, people using a supported decision-making agreement faced situations of risk, for which quick and appropriate responses were needed. In particular circumstances, people acted without a supporter, then realised that they may have made the wrong decision and shared the information, once they had legally acted. For example, they reported two cases, one about a cell phone contract and another about a bank loan with a credit card. In the case of the cell phone contract, it was possible to terminate the contract. On the basis of the will of the decision-maker, with a bit of time and energy, it had been possible to negotiate with the telephone operator to terminate the contract. For the bank loan, it had not been possible to void the contract but the repayment had been accepted without interest. The consequences could have been worse for the decision-makers but, thanks to the existing support network, people were aware of some risks and they realised that they should have asked for support. Because the support was in place and supporters helped to deal with the situation, decision-makers could quickly react to risky situations and learn from the experiences of solving “bad” consequences of a decision (CZ_INT_1).

The Bulgarian model created an evaluation of the risks in the instruments designed for people with intellectual and psychosocial disabilities (BG_DOC_1). Risk was included in the table for decision-making (tool) to be used for each decision for the former. For the latter, the initial facilitator questionnaire to get to know the person included an evaluation of the risks: it looked at risks perceived by their relatives and environment (and how it may influence the decision-maker), risks the decision-makers see and how they perceived fear for their own safety and well-being.

Last but not least, the concept of dignity of risk has been included in the new Colombian Act on legal capacity regime in the Safeguards principles as follows:

“Impartiality: The person(s) who are providing support for legal acts should always respect the will and preferences of the right's holder, independently from the fact that he/she thinks that he/she should act in another way, respecting the right to take risks and to make mistakes” (Article 5 – CO_DOC_9).

The next section explores relations and interactions with third parties.

7.6 Domain 6: Interactions with third parties

Domain 6 considered how the verification of who is a support person was conceptualised and delivered by the pilot projects. It also explored the experience of pilot project participants regarding interactions with third parties (how did third parties accept or challenge the work done by the supporters) and whether third parties offered or provided accommodation. Information related to this domain has been identified in four projects (Bulgaria, Colombia, Czech Republic, New York). The sources include mainly evaluation reports and policy documents as follow:

Bulgaria	BG_DOC_2	Policy document (legal aspects)
Colombia	CO_DOC_9	Law
Czech Republic	CZ_DOC_4	Evaluation of the experiences of participants in using decision-making instruments
	CZ_DOC_7	Policy document (legal and procedural aspects)
New York	NY_DOC_1	Evaluation report by external evaluator

This section contains relatively few answers. As the pilots have been concentrating on setting up support networks, and as supported decision-making is not yet or was not yet legally recognised in the pilot countries, the use of agreements in interactions with third parties (e.g.: doctors, bankers, notaries, municipal or state officials) has been very limited, if used at all. Few case studies illustrate the difficulties in working with third parties (section 1). The issues related to the recognition of support persons and the liability of third parties have been explored as elements of the new system (section 2).

Challenges faced by pilot projects in interacting with third parties

The pilot projects reported on some challenges, such as the lack of information about the existing instruments related to supported decision-making. The experience in the Czech Republic showed that the lack of information is a barrier in many situations where support for legally binding decisions is needed (administration, post office, employers, police officer, social security services, etc.). In many cases, participants reported that they needed to show the court decision, the agreement and also to give a number of additional explanations about the instrument, before their support arrangement was accepted. This did not necessarily mean that officials or representatives of some authorities were directly hostile or sought to obstruct the handling of certain matters, but their attitude reflected the fact they had no information about new forms of legal capacity. Therefore, they were cautious and even distrustful in the decisions presented to them and the decision-making processes. Participants identified this lack of information as a source of stress and a barrier for people with disabilities in implementing their decision (CZ_DOC_4).

Similarly, in Bulgaria, the pilot project staff reported that they were confronted with third parties who did not recognise the specific communication of individuals. In the case of one decision-maker, whose communication is non-verbal, the pilot programme had recognised the communication process between the person and his supporters and communication was clearly leading to decisions interpreted by others. Despite the evidence given to explain the method of communication and how the decision was formed, a notary refused to accept the decision of the decision-makers. "*For him, there is no legal evidence that he can accept this communication. And it is not only communication but also interpretation of the law*" (BG_INT_1).

Although the pilot projects have had limited interactions with third parties, they have explored how the recognition of support persons and the liability of third parties could be incorporated into the system for supported decision-making.

Recognition of support persons and liability of third parties at the legal and policy level

The Bulgarian pilot project recommended the establishment of a public register for support measures, within the National Population Register, inspired by the experience of the British Columbian non-profit organisation NIDUS[89], which keeps a voluntary register of Representation Agreements. Not all third parties would have access to the register, but only certain institutions (notaries public, banks, business organisations) (BG_DOC_2). Similar proposals came out of the discussion in the Czech Republic, although the fear of manipulation of data is a significant concern (CZ_DOC_7). A certificate for the supporters, as the court delivers a certificate for guardians, was envisaged. This option is seen as a good solution, to avoid using the full court decision, which is the only document they have. A court decision is indeed impractical and contains a lot of personal information. The question of creating a new registry is very sensitive given the

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[89] Nidus Personal Planning Resource Centre https://www.nidus.ca/ (last accessed 27/7/2021)

amount of personal information that it would include and who should access it. If data would be misused, it could be a source of information for discriminatory practice against people with disabilities. (CZ_DOC_7).

The New York pilot project worked with a different model without public registry: the signing parties for supported decision-making agreements are the decision-maker, facilitator, supporter(s), as well as a notary public. Both revocations and modifications require two witnesses, their signatures, as well as a notary public signature that the decision-maker authorised the changes. This model of certification by a Notary Public could work in the future, after the project has come to an end, with the legal recognition of a supported decision-making agreement to give it full effect (NY_DOC_1). The agreement itself has not been made publicly available so far, so the exact provisions they contain are not known. But the involvement of notaries public is an interesting alternative to the creation of a register.

Besides the issue of verification of who is a support person, interaction with third parties is a key issue in making supported decision-making a reality. It is necessary to ensure that the decisions are being implemented and executed by third parties.

At the system level, the Bulgarian model planned a high level of protection for the decision-maker: third parties who enter into a legal relationship with the supported person must perform an official verification in the register where a contract and/or court decision to institute supported decision-making is made. Third parties are required to comply with the contract. If despite the existence of an agreement for supported decision making, the third-party refuses to sign a contract with the decision-maker and does not initiate legal proceedings to review his or her status, the third party is liable for damages. But to start legal proceedings, the third party must prove *that it has made every reasonable effort* and despite this, it is not certain whether the person is protected from performing legal actions.

At the system level, the Colombian legislation takes a different approach which is more protective of third parties. It requires that the decision-maker uses the support that a court has determined that he/she needs in order for his/her legal act to be valid, failing which the concerned third party can consider this act as invalid (see Article 39 of the Law 1996). The law also specifies that this provision does not create an exception for the supporter from respecting the will and preferences of the person (CO_DOC_9) – in other words the supporter should respect the person’s decision. With this provision, third parties have a guarantee that the legal act is valid – through the use of the supports stipulated in the judgment. The law does not say anything about people acting without supports if the legal act does not go against the interest of the person. It is also silent on the question of what happens in situations where the supporters do not agree with the decision – is he/she obliged to support the person to give validity to his/her act and, if so, to what extent? How can the supporter pull back? Practice guidance will be needed to clarify how these provisions will apply in practice.

In the other countries, liability of third parties had not been considered given that supported decision-making agreements were not legally recognised.

The next section also deals with third parties and looks at the provision of reasonable accommodation in the exercise of legal capacity.

7.7 Domain 7: Reasonable accommodation

Domain 7 aimed to answer the questions on how the pilot projects worked with the provision of reasonable accommodation in the exercise of legal capacity for individuals or groups of individuals, whether they initiated reasonable accommodation with specific third parties and what was the participants' experience (e.g. did they obtain accommodation as requested or did they face denial of reasonable accommodation). This domain also considered whether pilot projects anticipated and put in practice special accommodation measures to include vulnerability in contracts.

Data relevant to this domain was available in documentation from five projects (Bulgaria, Colombia, Czech Republic, New York, Peru) and sources included mainly interviews and legal provisions as follows:

Bulgaria	BG_INT_1	Interview with project staff
	BG_DOC_5	Draft law
Colombia	CO_DOC_9	Law
Czech Republic	CZ_INT_1	Interview with project staff
	CZ_DOC_10	Project material: sample legal document (three-party agreement with bank, client, and supporter(s))
New York	NY_DOC_3	Academic article

This section about reasonable accommodation is brief as there was little available data on this topic.

The project material mentioned above shows that efforts have been made by project staff to use available mainstream instruments (PE_INT_1) and to work with several key professions, like doctors, bankers, notaries or lawyers (BG_INT_1). Sometimes the project staff made a little adjustment, such as updating the supported decision-making agreement "*which resembles a legal document, it has, as requested by self-advocates, the Decision-Maker's name in larger type than any agreement any of the lawyers among us have ever seen*" (NY_DOC_3).

The recognition of reasonable accommodation in the law was recommended by several pilots (BG_DOC_5, CO_DOC_9). Reasonable accommodation is for example one of the general principles of the Colombian law as stipulated in article 8, which gives all people the right to exercise their legal capacity independently with the necessary modifications and adjustments necessary to realise decisions. "*The capacity to act is presumed. The necessity of reasonable accommodation for communication or understanding information does not dismiss the presumption of capacity to realise legal acts independently.*" In addition, the law foresees several interesting procedural accommodations, for example, that the judgment will be produced in easy-to-read form for the person concerned as well as a guarantee for reasonable accommodation in the judicial proceedings about supports – for communication in the process or any other accommodation needed to satisfy the needs of the persons with disabilities (CO_DOC_9).

The next section is about formal and informal safeguards, which includes monitoring and review of supported decision-making arrangements and conflicts between supporters and decision-makers.

7.8 Domain 8: Safeguards

Domain 8 considered how pilot projects conceptualised informal and formal safeguards. Data was analysed to determine specifically what was envisaged and put into practice by the pilot projects:

- plans to advise and support decision-makers, supporters and third parties in case of doubts about their rights and duties
- the role facilitators play in safeguarding
- for monitoring supporters (including effective monitoring of informal relationships (avoiding unnecessary burden in the life of people with disabilities and their network members)
- how frequent regular review of support arrangements and safeguards take place and who facilitates the reviews

This domain also considered the mechanisms pilot projects have foreseen in case of conflicts or disputes between the supported person and the supporter, including support for a person with disability in a conflict, in order to guarantee his/her fair participation and the use of possible out-of-court mechanism(s).

Data relevant for this domain was available in the documentation of five projects (Bulgaria, Colombia, Czech Republic, New York, Zambia). The sources of data include mainly legal and policy documents as follow:

Bulgaria	BG_DOC_2	Policy document (legal aspects)
	BG_DOC_3	Policy document (economic aspects)
	BG_DOC_5	Draft law
Colombia	CO_DOC_9	Law
Czech Republic	CZ_DOC_6	Project material: sample legal document (supported-decision agreement)
	CZ_DOC_7	Policy document (legal and procedural aspects)
New York	NY_DOC_1	Evaluation report by external evaluator
	NY_DOC_3	Academic article
Zambia	ZA_INT_1	Interview with project staff

The pilot projects explored four main types of safeguards: participation, facilitation and trust relationships as key safeguards; safeguards to solve conflicts and disputes between decision-makers and supporters; safeguards in terms of type of decisions; and safeguards related to review and monitoring of support arrangements, the last two being essentially procedural safeguards.

Participation, facilitation and trust relationships: foundational safeguards

The obligation to respect the will and preferences of a person is the foundation of Article 12 CRPD and therefore it remains central in the different models developed by pilot projects. The principle that the person is at the centre of the process and must be involved at all stages of a procedure, in short, the participation of the decision-maker, is a foundational safeguard, which guarantees that the decisions are based on the person’s will and preferences (NY_DOC_3, CO_DOC_9, BG_DOC_2).

In the initial phase of the New York pilot project, people with intellectual disabilities and their supporters learn to speak up should abuse, neglect, exploitation occur, be threatened, or suspected. They also learn about their human rights, receive coaching on speaking up, and experience their decisions being respected by others, and experience greater self-advocacy. Supporters are informed that a risk factor for being taken advantage of is social isolation and that reliance on fewer people puts people with intellectual disabilities at higher risk for abuse (NY_DOC_1). This is an illustration of how the **participation** of the person is envisaged in practice as a fundamental safeguard. Decision-makers need to be equipped to enable them to participate.

Both the facilitation process and the supporters are also considered as foundational safeguards by the projects. Supporters are in themselves a safeguard, if their trusted relationship with the decision-maker can be demonstrated. The concept of **trusted relationships** as a tool for the expression of will (relationship based on mutual trust and understanding) is one of the main informal safeguards in the Bulgarian model. As described in section 6.2.1., a definition of such a relationship is difficult; several criteria have been determined to qualify objectively as a trust relationship (reciprocity, both people trust each other; no undue influence; existence of communication, ability to interpret the will and readiness to act in the interest of the person).

The third foundational safeguard is the **facilitation process**. While the projects have worked with facilitators for the piloting phase, they also have developed a model at the system level, where facilitators would be employed to create supported decision-making agreements (as a service provision). To guarantee that facilitation is delivered with good quality (the process respects the will and preferences of the person), the training of facilitators needs to be recognised, registered and facilitators need to be adequately monitored and have access to mentoring to reflect their work. In the Bulgarian model, the supported decision-making body (the mayor or a delegate) has the obligation to *“create and keep a register of the providers of the social service ‘supported decision-making’ and to create and keep a register of the organisations which provide training of the facilitators (…) and collect data about the training programs”* (Draft Law Article 8(2)). Similarly, in the Colombian model, a service of evaluation of supports is included in the law (Article 11): facilitators, working in public or private institutions, should be available in all the districts of the country (CO_DOC_9). In addition, the New York pilot project works with mentors who “*provide guidance as well as technical and emotional support to facilitators*” as defined in the project material (NY_DOC_1). Mentoring seems essential to face a large variety of situations and the complexity of relationships, which plays an important role in a support network. The mentors should also have an important oversight role in the development of supported decision-making, especially in the beginning (NY_DOC_1).

The New York pilot project also suggested organising peer-to-peer experience: online forums to provide a space for professional discussion between guardians, supporters and representatives for sharing good practice and for mutual support (community of supporters) (NY_DOC_1).

In the Czech Republic, the project has designed an Institute for Supported Decision-making (hereinafter referred as the Institute), the role of which would include guidance, monitoring and a “community” of involved persons, as the facilitation process. The Institute would be responsible for the following:

- To provide information and advice to both supporters and supported persons. Work with experts in more complex cases.
- To educate both supporters and supported persons, organise thematic trainings open to all.
- To provide methodological guidance for supporters, including basic guidance for working with risk.
- To collect good practices and use them to develop methodological material.
  (CZ_DOC_7)

Safeguards include a system to solve conflicting situations between decision-makers and supporters.

Conflicts between the decision-maker and the supporter

Because the justice system globally has contributed and still contributes to the preservation of the substituted decision-making model, the pilot projects are looking to improve access to justice for people with disabilities but also to establish out-of-court alternatives. Both issues were addressed only superficially but some potential routes have been explored by pilot projects.

In terms of access to justice and procedural safeguards, a key provision included in the Bulgarian pilot project is that the decision-maker should have the opportunity at any time to start proceedings for implementation, modification or termination of the support measure. They should be granted the right to participate personally in all related administrative and/or judicial procedures, to express their will, to submit applications and to receive legal assistance. This is of utmost importance in case of conflict or an unsatisfactory relationship between the supporter and the decision-maker. People close to the decision-maker and professionals who work with him or her, including civil organisations whose activities are related to people with psychosocial and/or intellectual disabilities can also initiate a procedure to protect the rights and interests of the decision-maker. It can prevent or solve conflicts between supporters and decision-makers (BG_DOC_2).

Outside of the justice system, mediation is a key element which has been explored by different pilot projects. The New York pilot project plans the creation of a mediation protocol for resolving conflicts between decision-makers, supporters and/or third parties in collaboration with the Mediation Clinic at CUNY Law School during the project fourth year. Such a partnership with existing centres could be beneficial for several reasons. These centres exist in every county and provide trained volunteers for dispute resolution and conflict coaching. Thus, the organisational structure, as well as the skill set of its volunteer mediators seems to be of great advantage, not to mention that it is a mainstream service. The New York project staff envisioned that challenges related to supported decision-making could be handled by volunteers who would receive additional training on supported decision-making (the project foresees a two-day training on supported decision-making, the facilitation model, and potential disputes that may arise). In addition to conflicts between supporters and decision-makers, the project staff thought about enlarging mediation to other possible conflicts: between supporters and family members or other close persons to the decision-maker who were not chosen as supporters, and between the decision-maker and provider agencies who may be unwilling to accept her/his decisions about services they offer or withhold (NY_DOC_1, NY_DOC_3).

Similarly, in the Czech Republic, there has been thinking about using mediation techniques and the existing mediators' network for resolving conflicts between supporters and supported persons (CZ_DOC_7). The model of the Institute, as designed by the pilot project, would be the first place a decision-maker should turn to and the institute would handle basic complaints and disputes as well as look at professional mediators. In case of abuse, the Institute could go to court immediately to raise the alarm about the situation.

Safeguards in terms of types of decisions

There is a general consensus that not all decisions can be supported in the same way. Some specific and important life decisions need additional safeguards, as the risk of their abuse is high. The Bulgarian model developed safeguards for the right to marry, the right to make a will, freedom of association and the right to vote. In addition, with regards to the place of living, several procedural safeguards have been included to protect the decision-maker from being placed in a living arrangement he/she did not choose.

Additional specific provisions for the right to marriage and family, reproductive rights, will (disposal of property or estate after death), freedom of association and the right to vote have been proposed. For each one of those areas, general support measures (such as interpreter, free legal advice) and supported decision-making measures (such as support in the exercise of parental rights, access to specific aids and others) have been included (BG_DOC_2).

With regards to consent to live in an institution, a special court decision is needed as a safeguard against unwanted placement. The judge should check that the decision-maker's consent was given on the basis of information about the institution; the placement by a court decision can be done for a limited period of time and only after checking that there are no community-based alternative. The person should have direct access to an appeal procedure; and periodic judicial review of the placement and its duration should be conducted (BG_DOC_2).

The last sub-section explores the mechanisms for review and monitoring of support arrangements.

Review and monitoring of support arrangements

Pilot projects have been looking at changing the focus of traditional guardianship reviews on finances and assets by monitoring the trust relationship, and how the support relationship works. This is why pilot projects have set up different criteria and enlarged the group of persons who can participate in the monitoring process.

These formal safeguards are based on the principles of **necessity, proportionality and tailor-made principles**.

Monitoring support arrangements means regular review. Each pilot project has set a regular review by limiting the use of an instrument to a short period (1, 2, 3 or 5 years) depending on the countries. Apart from the length, a more important factor is the participation of people who may have an opinion on the way the support arrangement works.

A yearly review for agreements approved in court consisting of a meeting with the judge, which is open to additional persons who can demonstrate their interest, is the procedural rule chosen in Colombia. People who are close to the decision-maker and people from the community are asked to confirm that the support relationship is good or on the contrary to report about abuse or manipulation (CO_DOC_9). A 5-year review is planned for agreement of support approved out-of-court (CO_DOC_9).

The Bulgarian model proposes 2 or 3 years depending on the source (BG_DOC_2 / BG_DOC_5). The Czech Civil Code does not foresee any regular review for mechanisms other than partial guardianship. The idea developed in the model is to include a regular review by the Institute for Supported Decision-making which should be in charge of regular biennial monitoring. The Institute should be able to request documentation and face-to-face meetings focusing on quality of the support and relations. This would of course imply a modification of the Civil Code or at least the Act on Special Judicial Proceedings (CZ_DOC_7).

The last section explores the issues related to the costs of the support.

7.9 Domain 9: The costs of the support

This domain considers whether the pilot projects analysed what resources are needed for formal decision-making with support, what resources are needed for decisions made on the best interpretation of the will and preferences of individuals who have no previous experience of making decisions for themselves, what resources are needed to create a support network for people who have no relations or are socially isolated (the work involved by how many people, how much time and other resources). This domain also looked at potential benchmarks set up to evaluate the quality of life with the supports provided in the exercise of legal capacity to pilot projects participants.

Information relevant to this domain was limited, as only Bulgaria conducted an in-depth analysis. Two other projects have simply shared thoughts about the issue of costs (Peru, New York). Sources of data include policy and academic documents as follow:

Bulgaria	BG_DOC_3	Policy document (economic aspects)
Peru	PE_DOC_1	External evaluation report
New-York	NY_DOC_3	Academic article

Only one country, Bulgaria, has conducted a cost effectiveness analysis looking at the financial and non-financial benefits of supported decision-making. The analysis measured quality of life before and after the project, as well as quality of life in the community and in institutions (non-financial benefits)[90]. The research also estimated the costs of supported decision-making versus the cost of guardianship (an average estimation per person per year, including initial costs and costs for implementation of a 10-year period gives the following numbers: guardianship 208 BGN (approx. 88 GBP), supported decision-making 699 BGN (approx. 296 GBP), so the financial difference amounts to 491 BGN,

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[90] personal outcome scale (POS) and WHO Quality of Life (WHOQoL) – see inspiring practice 9 in Annex No. 7.

208 GBP). And the analysis also included the costs related to the use of social and health care services as well as employment e.g.: residential and housing services and day care centre, advisory services, as well as health services, comparing an ideal situation with the current situation, taking for granted that supported decision-making improves the skills of the people (for both people with intellectual and psychosocial disabilities). Their conclusions showed that supported decision-making is more expensive than guardianship but that the end of institutions (de-institutionalisation process), a reduction of the length of stays in psychiatric hospitals and an increasing number of people with disabilities in employment, as a result of better support and increased skills, would be beneficial, without doubt in non-financial terms (quality of life) but also in terms of financial terms (less dependent, more autonomous and productive people) (BG_DOC_3). The cost analysis is concluded with the following statement: *"as a result of the supported decision-making in comparison with the system of guardianship the society receives non-financial benefits in terms of 'Improved quality of life, equality before the law (Article 12), independent living and social inclusion (Article 19)'. The non-financial benefits have in the case of supported decision-making much more weight. Quality of life, respect for human rights, independent living and social inclusion of people with mental health problems and intellectual disabilities are social benefits which should be leading to the decision to change the system of guardianship. They have no monetary value because they are priceless"* (BG_DOC_3).

In terms of costs, some considerations can also be found in documents from other pilot projects. The evaluator of the Peruvian project in his conclusions noted that the realisation of individual plans would not allow enlarging the network of supporters to new persons. It would have required far more intense work than what the staff of the project could have been able to achieve with the time and the resources available (PE_DOC_1).

The New York project leader, without conducting a similar analysis as in Bulgaria, reflected on possible parallel with the findings from the Bulgarian costs analysis. *"The SDMNY pilot has, we believe, demonstrated that supported decision-making weighs heavily in favour of the 'human' and social benefits to Decision-Makers and their families in the form of greater self-determination, possibility for growth, autonomy and dignity, as opposed to the costs of guardianship, under which persons subject to guardianship can, according to the National Council on Disability, 'feel helpless, hopeless and self-critical', experience 'low self-esteem, passivity, and feelings of inadequacy and incompetency' as well as significantly decreased 'physical and mental health, longevity, [and] ability to function.'"* (NY_DOC_3). In terms of economic benefits, the project leader finds it difficult to quantify them. Looking at the arguments of community housing, more skilled and autonomous people with disabilities and reduced administrative hassle, she believes that they may be economic benefits but that the benefits are mainly to be seen in terms of rights, dignity and quality of life.

While, the Bulgarian pilot project is the only one to have a proper cost analysis, the other pilot projects have noticed the non-financial benefits of supported decision-making and have observed at the same time, both for people with and without networks, that there is an important human factor: the time invested in setting up networks and preparing decision-makers and supporters for their new role.

In conclusion, the questions relevant to the nine domains of the framework remain in large part unanswered. However, the practical and theoretical experience of the pilot projects provides a number of elements which can enlighten and foster the implementation of Article 12 CRPD.

8 Implementation of Article 12 CRPD: Synthesis of Outcomes, Gaps and Emerging Issues

The domains of the framework offer a mechanism for analysing whether and how Article 12 was being implemented by the pilot projects. While the analysis of the pilot projects presents several limitations, their outcomes provide a positive contribution in advancing implementation of Article 12 and also highlight further questions and gaps for future research. Outside of the nine domains analysed in the previous chapter, the experience of pilot projects shows that additional structural barriers and challenges need to be solved to advance Article 12 implementation.

8.1 Limitations of the work of the pilot projects and of its analysis

The lack of data, the inherent nature of pilot projects and the analysis of the work based on documentation and interviews are all limitations to this work.

As mentioned in chapter 5, less data was available for the pilot projects in Zambia and Peru than for the projects in Bulgaria, in the Czech Republic, Colombia and New York. Short-term projects also produced a limited amount of material and had less experience to share about the know-how acquired during the pilot.

The analysis of the pilot projects' work is also limited by the sources used: pilot projects documentation and interviews with project staff. Material about the pilot projects was not always publicly available. In most cases, material was shared by project staff, but sometimes only a selection of documents. In addition, there was no observation on the ground or direct interviews with project participants. Several reports or analyses included participants' voices and opinions with direct quotations, which was a very valuable source for the analysis. However, each document was designed differently with its own objective and therefore the content was diverse and was not intended to be compared. Voices of participants however gave strong messages about the results and the impact of the pilot projects.

While Article 12 CRPD is the main reference for all pilot projects, it is worth noting that the pilot projects looked at the practical steps to make support for decision-making a reality rather than answering theoretical questions around legal capacity, thus sometimes not critically reflecting their work in relation to Article 12. So, there is a gap between a) the questions of the framework, which were formulated on the basis of the literature around Article 12 concepts of legal capacity and supported decision-making and b) the data available in the pilot projects, which looked at support in practice and in everyday life.

This gap between the theory and practice explains the lack of data relevant to the nine Article 12 domains: very little data was available for analysis in relation to the more complex questions of the framework. This is the case for Domain 1 (Being a person before the law), or questions related to complex situations, such as when preferences are unclear, conflicting or absent, emergency situations or situations of serious adverse effect. These situations may simply not have happened during the project implementation.

In addition, available data corresponds mainly to the micro level of a system of supported decision-making, the individual level.

The findings show that data is available on the topics of support needs and support networks: identifying the support needs, not only in decision-making but in general, and the potential supporters who can play a role in the decision-making of an individual. Available data corresponds to the beginning of a process: the set-up of a supported decision-making arrangement. The pilot projects also provide information and data about developed practice guidance and/or training material for supporters and facilitators.

Data is scarcer in relation to the implementation of supported decisions or the use of anti-crisis plans. This can be explained by two factors: the pilot projects were too short in time or spent too much time on identifying support needs and supporters (a number of projects acknowledge delays in the realisation of project activities, see for example PE_DOC_1 or NY_DOC_1).

Regarding the mezzo and macro level, several elements were developed theoretically by some pilot projects, but they could not be tested in the framework of the projects, because they did not have the necessary institutional partners to pilot some activities (e.g. testing procedural accommodations or evaluating the adoption of measures of supported decision-making in the judiciary).

In terms of interaction with third parties and reasonable accommodation, the mezzo level of a system of supported decision-making: these two areas of the framework have not been given priority in the pilot projects and testing measures would have implied strong collaborations with third parties. The data collected around third parties is far more related to advocacy[91] and campaigning work towards selected stakeholders.

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[91] The term *advocacy* is used here in the sense of pleading for a cause, campaigning for a cause, not to act as advocate for someone.

The long-lasting pilot projects have designed elements of a supported decision-making system, including the macro level. The level of description of those elements varies significantly between the pilot projects – sometimes they are expressed more in the form of questions or elements to be thought of rather than providing a concrete provision or model. In Colombia and in Bulgaria on the contrary a detailed legislation has been drafted. Policy and legal changes could not be piloted and tested in practice, but some projects have made valuable descriptions of the necessary policy and legal changes.

The framework questions remained largely unanswered or only partially answered in most cases. The length of the pilot projects, the fact that material and practice guidance were developed and tested during a limited project time and the fact that supported decision-making is not yet or was not yet legally recognised in the pilot projects countries are all factors limiting the availability and the verification of data. However, despite their limitations, as discussed next, the pilot projects have made a positive contribution to the learning on how best to advance the implementation of Article 12.

8.2 Pilot projects' contributions to the implementation of Article 12

First of all, a clear finding is that pilot projects made a real change in the life of people with intellectual or psychosocial disabilities, by putting the individual at the centre of an empowering process, by respecting his/her rights, will and preferences and by considering that person as the decision-maker. The practice guidance documents and the evaluation reports show that it is not only declaratory, it was put into practice. It is important to underline that a positive impact on people with disabilities was observed in all the pilot projects. Decision-makers have usually gained confidence and self-advocacy skills and have grown up (NY_DOC_1; PE_DOC_1; BG_DOC_3, CO_DOC_8, CZ_DOC_3). In Peru, the evaluator found increased skills in household, clothing, but also communication and relational skills (better oral expression, creating new relations, friendships), privacy, the use of an ID card, how to sign, money management (three people newly using debit cards) and job opportunities, all bringing more autonomy and independence (PE_DOC_1). In Bulgaria, both groups of people with intellectual and psychosocial disabilities were observed: the greatest improvement is registered for both groups in the domains of personal development, self-determination and interpersonal relationships. Personal development and self-determination are exactly those two main domains determining and contributing to the greatest extent to improvement of quality of life (BG_DOC_3).

In this sense, the pilot projects confirm the importance of Article 12 in terms of self-determination and that implementing supported decision-making is a worthy process.

For each domain of the framework, the pilot projects contributed to the implementation of Article 12 in some way.

8.2.1 Domain 1: Being a person before the law

The pilot projects have considered legal capacity on an equal basis with others, as stated in Article 12 CRPD, assuming that people with disabilities have full legal capacity (or may recover legal capacity, for those who were under guardianship) and they have been given such status throughout the projects. This first domain of the framework was however not explored further. The pilot projects did not attempt to conceptualise and test criteria demonstrating one's decision-making capacity – in other words to find alternative thresholds or mechanisms for those who do not meet the traditional test of legal capacity. As described in paragraph 6.2.1, only the Bulgarian model proposed an alternative threshold for those people: a lower threshold based on trusted relationships as a tool for expressing the will of a person with a disability. It is an essential element in guaranteeing legal capacity to all because it provides an alternative. It echoes paragraph 8(2) of the British Colombian Representation Agreement Act, which includes a trusted relationship as a threshold for entering into a Representation Agreement. But the Bulgarian model goes further by suggesting four criteria for which evidence of a trusted relationship can be provided in legal capacity proceedings (see section 6.2.1: 1. Trust, 2. No undue influence history of abuse and violence, 3. Communication and stability of the relationship, 4. Readiness to act in the interest of the supported person). This is of utmost important to assess a trusted relationship, a notion that can hardly be defined and could be interpreted by each individual differently. These criteria have the advantage of being wide-ranging, open to all forms of evidence and based on multiple sources, and therefore they can be inclusive also for people with severe disabilities (BG_DOC_2). Practice will show how the assessment of these criteria will be undertaken but it provides an important element to maintaining legal capacity and equal recognition without discriminating on the basis of a disability.

8.2.2 Domain 2: Determination of support needs

Article 12 guarantees appropriate measures to provide access to the support persons with disabilities may require in exercising their legal capacity. The pilot projects have designed several instruments to determine support needs to exercise legal capacity. This included communication needs, by whom decision-makers want to be supported, in which area and how. To provide access to support or to identify sources of support, projects have worked with a "facilitator", a new position dedicated to the determination of support needs and the individualised design of supported decision-making measures.

The assessment of support needs however lacked a proper instrument. Some pilot projects created a tool for the assessment of support needs, but no such information about how the tool was revised or improved could be found in the documents analysed. An evaluation of the mapping instruments and the tools to assess support needs should be developed, as this information was missing in the pilot projects documentation.

One key question, related to the use of such instruments, is the need to better distinguish support to exercise legal capacity and skills for autonomy of life. The evaluator of the pilot project in Peru pointed out that challenge when noticing that progress can be seen in the context of autonomy of daily life more than in the exercise of legal capacity (PE_DOC_1). The Colombian model includes proposals for training skills for individuals for whom it can benefit, as part of the assessment for support needs. These proposals are independent from the support measure resulting from the assessment, in the sense that it is not a pre-condition to it. These accompanying measures are proposed to strengthen autonomy, to ensure that the capacities of individuals are maximised (CO_DOC_9).

Another key question is the participation of the decision-maker in determining his or her support needs. The pilot projects either involved close relatives in the process or did not involve them at all. In the model developed by the New York pilot, decision-makers make independent decisions about who should provide them with support and how. This does not seem fully adapted to people with more severe disabilities who need support in communicating their will and preferences. Excluding future or potential supporters also provoked several criticisms and distrust from the families in New York. In other pilot projects where relatives have been part of the process, the presence of other participants may have influenced the choices and preferences expressed by the decision-makers. Some elements of reflection and discussion about the involvement of relatives appear in different project material. The right balance needs to be found between the participation of relatives in the process as partners while allowing genuine choices about decision-maker's support arrangements. This aspect should be further explored as well as how to maximise the involvement of the decision-maker in this process.

The pilot projects have however made a great contribution by giving primary importance to the assessment of support needs in the process of attributing formal supports and by shifting from the identification of lack of capacity to the assessment of support needs.

The Colombian and Bulgarian models gave a prominent role to the assessment of support needs, involving a facilitator or a multidisciplinary team whose opinion needs to be followed. This model limits the power of the judge whose decision has to respect the conclusions of the assessment of the facilitator. It is an important element to shift the focus around support needs rather than the traditional psychiatrist assessment. It brings a fundamental change in legal capacity proceedings, previously often characterised by a diagnosis-based and paternalistic approach of the legal capacity of people with disabilities.

The combination of legal and social work which has been put in practice by all the pilot projects in an ad-hoc or more systematic way (Bulgaria, Czech Republic, and Colombia) may also facilitate this shift. Proposals for supported decision-making arrangements made in collaboration between a social worker and a lawyer provide solid legal and factual arguments for court proceedings, as the work of the pilot projects have proven.

While the legal system needs to be reformed at the macro level, it is also important to "translate" the results of social work in legal terms at micro level: e.g.: showing that the dependence of care is compensated by several supporters which can monitor each other, explaining how risks are mitigated to avoid legal transactions that may have negative consequences, etc. Collaboration between a lawyer and social worker or case manager has proven to be useful to "translate" these social aspects in legal terms. It gives solid legal arguments where a safely functioning system of support can be set. In the Czech Republic, this was a key to successfully getting an agreement on supported decision-making to be approved by judges: *"we just tried to find arguments, or to find out if the situation does meet or not the condition to limit capacity, which is a risk of serious harm to that person. So we had to look at whether there is a risk of harm, and just identify the risks and suggest how the risks would be mitigated"* (CZ_INT_1).

Pilot projects also implicitly demonstrated that there is no systematic need for formalised support measures and that support can be provided, in some cases, informally with a good assessment of support needs. It reiterates the importance of natural supports in the community as the primary model for supported decision-making. It confirms that both formal and informal support for decision-making should co-exist, and that the right to support should be guaranteed also for people who are able to make independent decisions. It echoes in practice the notion of "continuum of support", having a cluster of supports at one’s disposal (Bach, 2006). It also brings attention to the risk of over-legalisation of support, which should remain informal where possible.

8.2.3 Domain 3: Available supports

Pilot projects have been successful in offering or at least designing as an element of the system, a range of support measures available for persons who may require support in exercising their legal capacity. They have combined existing measures (not necessarily available in their country but in others), including measures related to decisions in the area of finances and assets, specifically mentioned in paragraph 5 of Article 12.

By doing this, pilot projects have reiterated that there is expertise in the disability field, offering support measures which already existed (e.g.: peer support, mentoring, alternative communication methods) but also by identifying mainstream measures that could be used as support measures for people with disabilities. In the countries where this pragmatic “scanning” of what already exists was done, this exercise provided interesting results. It showed that there is already experience and practice on which supported decision-making can be built.

The richness of the measures proposed by some of the more advanced projects confirms in practice the analysis made by several academics about the several categories of options available, and most importantly, that these categories could be enlarged and evolve with time (Gooding, 2013, Minkowitz, 2007). This scanning should be done systematically to provide access to existing measures.

This said, all the projects have primarily worked with supporter networks, the most frequent measure. While support networks are a key measure, pilot projects did not really explore other innovative support measures or combinations of support measures. This raises the question of the risk of working with a “one solution fits all” model. Several options should be tested to gain experience not only with support networks, but also involving professional supporters or peers, for example. It echoes the discussions around the lack of definitions and the lack of clarity of the term “supported decision-making.”

This also relates to the question of the choice of support instruments and the involvement of decision-makers in this process. The pilot projects explored the will and preferences of the decision-makers in setting the support arrangements and planned their involvement in revising those arrangements. But as mentioned earlier, some pilot projects also aimed at realising life plans and dreams. This partially stirred pilot projects into an empowerment project rather than supported decision-making. It shows the danger of focusing on bigger decisions and plans, while support for smaller day-to-day decisions is not in place (there is a lack of decision opportunities).

Article 12 should also be implemented within the Convention's general principles of full inclusion and participation of persons with disabilities in the community. The pilot projects have all explicitly or implicitly linked Article 12 to Article 19, thus giving substance to the statement by the CRPD committee that *"support in the exercise of legal capacity should be provided through a community-based approach"* (CRPD, 2014). Mapping the environment and matching it to a person has been part of the process of building supports. It is a way to make the best use of what is available out in the community and ensure that it matches the preferences of the person. It is not about making their preferences fit in what is available, but it is the pragmatic answer to building community supports based on individual preferences. By compiling the efforts of all the pilot projects we can identify four elements of the work with the environment:

a) Mapping the resources available in the community (e.g. the Ecomapa in Columbia) in terms of persons and services
b) Dealing with the risks and safety issues that are specific in that community
c) Giving a valued role to the person with a disability in his/her community: as a volunteer, as a worker, as a citizen or just as an active person
d) Making the environment more accessible: not for only one person but by challenging the system to be more accessible and friendly to people with disabilities (see the domain of the framework about reasonable accommodation)

At the same time, pilot projects have confirmed that informal and formal supports are interlinked and interdependent. It echoes the academic discussions around the continuum of support and the enabling conditions as different tools available for support in exercising legal capacity and reasonable accommodations which are provided all the time, allowing individuals to move from one cluster to another one (Flynn and Arstein-Kerslake, 2014a).

8.2.4 Domain 4: Supporters' role: duties and liabilities

The findings of this domain are essential for the implementation of Article 12 in many ways. First of all, some pilot projects demonstrated their capacity to create and enlarge networks to build circles of support. While this is clearly a long-term objective, beyond the duration of the project, it gives a clear answer to the question of supported decision-making of isolated people: it is possible to build new networks for them.

This positive message, however, should not hide the complexity of this issue. The successes achieved by pilot projects implied a certain amount of finances and intense work load for a small amount of people. In the last domain of the framework, the question of the costs of creating a support network will be posed. Apart from the question of the costs, it poses the question of the access to support for people who have no trusted relationships. How to guarantee that all isolated person will benefit from such a work? How to make sure that they do not become the one group remaining under guardianship? The CRPD Committee has taken a very clear position that Article 12 does not fall under the provisions of progressive realisation: *"The State obligation provided for in Article 12, paragraph 3, to provide access to support in the exercise of legal capacity is an obligation for the fulfilment of the civil and political right to equal recognition before the law. 'Progressive realisation' (art. 4, para. 2) does not apply to the provisions of Article 12."* There is a discrepancy between the long-term results and impact of social work in developing and maintaining a network and the ambition of the Committee that all persons should have access to support. It raises the question of intermediary steps or transition measures, which have been outside of the scope of pilot projects.

Secondly, pilot projects have proven their capacity to create diverse material to help supporters understand their new role. Even in the short-term, projects brought benefits for the supporters. Pilot project documentation showed that people think differently or at least start to do so. Those may be small but important changes, like seeing the person as an adult and not as a child anymore, and thinking about involving the adult in conversations about decisions. In the same way, several projects report changing the way an organisation works, the way staff members see things and works (BG_INT_1). Being in a position of supporter, respecting the rights, will and preferences of the decision-maker, make people change their attitude. The pilot projects created guidance and training aiming to "reposition" supporters in their new role, moving from being the main decision-maker to being an aid to the decision-maker (NY_DOC_1). The workshop sessions in Peru show how important it is to have time dedicated to supporters (the pilot included eight sessions every two weeks). The evaluator even suggested reinforcing the training for carers, for example: increase the number and the frequency of the training sessions, to include more family members, to include a co-trainer from the local area, also a carer of a person with intellectual disabilities, to increase the participation and to guarantee the sustainability of the project, to pay more attention to people with low education (PE_DOC_1). In short, more staff should be involved.

This is again a promising element to make the “will and preferences” paradigm a reality and to replace the “best interests” paradigm. It shows that a change of culture (in families, but also in services and in the community) is possible by educating and accompanying supporters.

Regarding liability of supporters, pilot projects have created some materials which can serve as a basis for further experience. It will need however to be tested in practice, as there was no information about solving cases of liability issues in the pilot projects.

8.2.5 Domain 5: Supported decision-making processes

This domain of the framework is maybe the most difficult to assess through project documentation, while not being able to observe the work on the ground.

One of the primary criticisms of supported decision-making to date has been the lack of empirical evidence as to whether it really works, and whether the decisions made under supported decision-making are, authentically, the decisions of the decision-maker (Kohn et al., 2013). In other words, it questions whether supported decision-making would simply hide substituted decision-making under new and seemingly more respectful packaging.

This research aimed to find more information and data about supported decision-making processes. Two principal barriers to the accessibility of these data are the lack of reporting tools and the lack of time and space for such detailed work.

There is almost no data about the history of decisions made within the pilot projects and therefore it is not possible to track records of supported decisions and analyse how decisions works in practice. The projects did not foresee instruments to track and report about decisions. Therefore, the data about decisions (what decision, who was involved and how the decision was reached) may be available to some project staff but was not systematically recorded. The field journal in Colombia was the most detailed material available but it contained much more information than the decision-making and was not anonymised in a way that would allow working further with it.

Some evaluation reports (PERU_DOC_1, CZ_DOC_4, NY_DOC_1) gave feedback about how people are happy with their supported decision-making arrangements, about being able to make decisions on their own (there is a comparison of before and after the project), about learning new skills (e.g., very often related to money management) but there is not enough data to assess the process, that is to say, how the decision-maker was supported to make a specific decision, what support techniques or methods were used and how decisions were implemented and then evaluated.

While a number of indications show the more frequent involvement and participation of people in their own decisions as well as the satisfaction of decision-makers it is not possible to conclude that they represent the views of the persons. It can only be assumed that a more respectful process gives better results.

Shorter projects focused on setting up an agreement and/or a support network and not on its implementation. Longer projects have sometimes included work on a specific goal (to find a job, to live on one's own) and therefore no space and time has been dedicated to reporting decisions.

The projects have been an opportunity and an incentive for families and supporters to change and make efforts to adapt to their role. On the other hand, not everybody started from the same point and it takes time to move from substituted to supported decision-making, as this is the result of a learning process. Another way to measure supported decision-making processes would be measuring progress on a scale from substitute to supported decision-making reflecting individual characteristics and needs. That would give empirical evidence over time that supported decision-making works by reflecting progressive changes and potential regress at certain points. The available data describe the process of empowerment, an issue which will be explored among the emerging topics in the following chapter.

Similarly, accessing detailed reports about situations where will and preferences are absent, unclear or conflicting has not been possible. Only some case studies were reported by the pilot project staff – all of them are positive, in the sense that a satisfactory solution has been found with the decision-maker.

The mechanisms proposed in the Czech and the Bulgarian models will need to be refined with the experience of more and new cases.

8.2.6 Domain 6: Interactions with third parties

This domain is of course one of the most difficult areas to be tested by pilot projects, in countries where liability of third parties is not yet established, as supported decision-making agreements are not yet legally recognised.

However, the pilot projects reported a general lack of information and awareness of third parties in general about people with disabilities. This relates to another general obligation under the CRPD – Article 8 regarding awareness-raising about people with disabilities, their abilities, and also the use of reasonable accommodation. This is needed before concrete information about supported decision-making arrangements.

Issues related to the recognition of supported decision-making measures and liability of third parties emerged in the pilot projects material.

First of all, the models designed by the pilot projects posed the question of public register versus notary, for example. The question of a public register is very sensitive because, if obligatory, the question of who can access information and what information should be available will need to be carefully considered. There is a risk of discrimination and potential misuse towards people listed in the register. At the same time, the system would be uniform for all and the access can be controlled.

Involving a notary public is an interesting option as it is also a way to keep the procedure out of court. But it raises the question of the price – a notarial act is a paid service. And there is the more complicated issue of the acceptance by the notary of a supported decision-making agreement. What if the notary refuses to certify the process, because he/she cannot accept that it is the person’s will, even with lower threshold of legal capacity? What should the appeal mechanism be? Is there not a risk of reinforcing a barrier in the system, by creating a shadow list of “good” and “bad” notaries? Could this create an unbalanced system which would not be available to all?

The models designed by the pilot projects also included some provisions about liability. Again, confronting different approaches shows the delicate balance between the right of the decision-maker to decide and the right of third parties to enter, modify or end secure transactions. The Colombian model stipulates that a legal act made by a person who benefits from a formal support measure (by court decision) is guaranteed by the use of supports, otherwise the act can be voidable. Can this provision be considered adequate and proportional? If the person does act in a way that does not damage him/her, and that does not contradict other decisions, why would the person have to make use of his/her support measure? The fact that the act can be voidable denies the right to decide of an individual and to choose to use his/her support. On the other hand, the decision-maker has agreed and accepted to be supported in certain areas of decision-making, because he/she needs support. Does that justify then the systematic and obligatory use of the support measure?

8.2.7 Domain 7: Reasonable accommodation

The right to reasonable accommodation is transversal throughout the CRPD, and a specific right included in Article 5 about non-discrimination. However, it has not been explored in the pilot projects as a complementary aspect of the right to support in the exercise of legal capacity. Some models included the recognition of reasonable accommodation as such in the law, but a limited number of activities (e.g.: accessible information) explored what accessibility and reasonable accommodation means in the context of legal capacity. The narrative review already showed that the obligations concerning the provision of reasonable accommodation are unclear. How to use the right to reasonable accommodation as separate from, and complementary to, the right to support in the exercise of legal capacity still needs to be clarified. For example, when is communication assistance part of a support measure (support network assists in decision-making and in communicating the person's intentions to others) and when reasonable accommodation (in the case of a person with full legal capacity and no support measure).

Accessibility in the context of legal capacity as well as accessibility of the justice system, including of court proceedings and out of court measures such as mediation should be explored in more detail, taking into account Article 12 in conjunction with Articles 9 and 13, as persons before the law with equal standing in courts and tribunals.

8.2.8 Domain 8: Safeguards

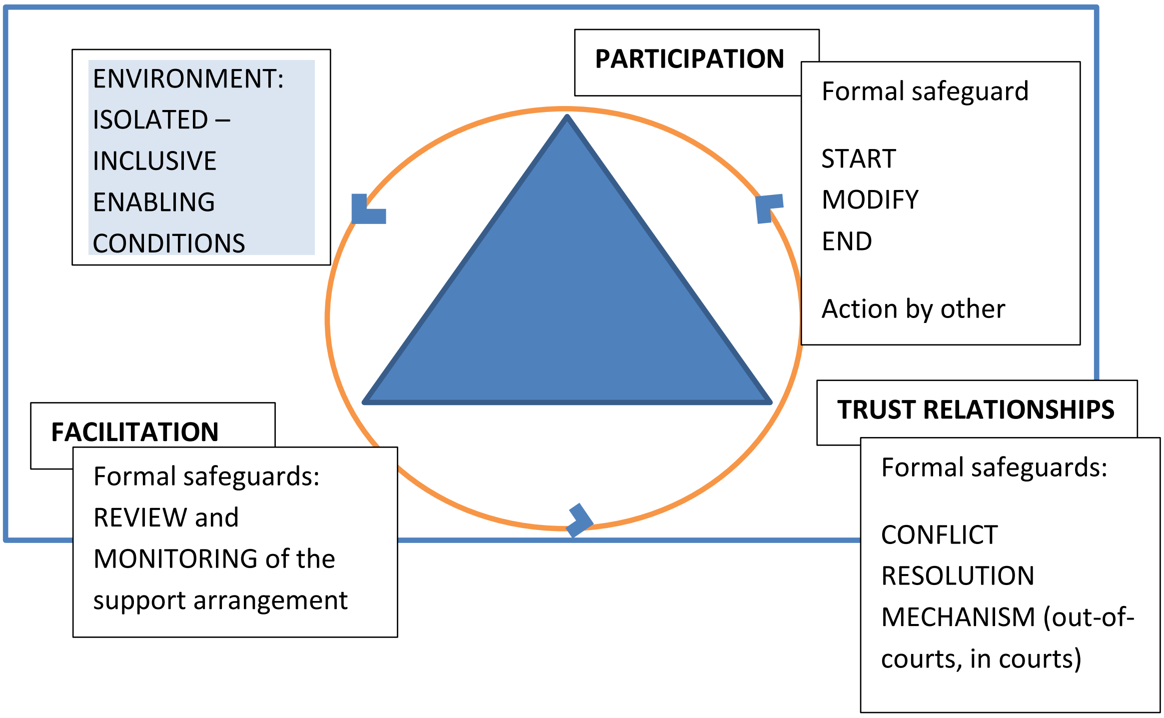
Safeguards is an important section which relates to the whole paragraph 4 of Article 12. Many safeguards have been explored in the pilot projects, on a theoretical and practical basis. From the pilot projects experience, a trio of foundational safeguards emerged as the basis for support in exercising legal capacity: participation, facilitation and trusted relationships. These three foundational safeguards can be completed by other formal safeguards. Participation, facilitation and trusted relationships are three elements without which there is no model based on will and preferences possible. These three important elements guarantee that the will and preferences are respected, as safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected.

The triangle of fundamental safeguards is represented in the following graph, where the three elements should be encouraged or promoted. Indeed, when there is no trust relationship or very few – relations can be built as a "complementary" activity to the process of facilitation. Similarly, participation may need to be trained and encouraged to make sure decision-makers become active and learn to speak up. Participation can also be fostered for people with severe disabilities. This is why this simple scheme of safeguards is presented as a dynamic process: participation and relationships need to be fostered and developed thanks to the facilitation model. The environment in which each person with a disability is evolving (on a scale of isolated to inclusive/participatory) will influence the intensity of the process. The available support measures (enabling conditions) will be different in each jurisdiction.

PARTICIPATION is safeguarded when a decision-maker can start, modify or revoke any agreement or another measure of support. Action should also be possible by related persons or organisations, as in the Bulgarian model, to guarantee that this safeguard is also accessible for people with severe disabilities.

FACILITATION process: can take a different form and can be performed by persons with different backgrounds in different settings. It is safeguarded by the validation of the facilitation process and the support arrangement (e.g.: notary, court) and the review and monitoring of the support arrangement.

TRUSTED RELATIONSHIPS: are fundamental for support arrangements. However, conflicts may arise, so besides conflict prevention, a formal safeguard in the form of accessible conflict resolution mechanism is needed, for example, out-of-court mechanisms such a mediation, as proposed by several pilot projects.



The work done by pilot projects suggests that a system of safeguards could be built around this triangle of fundamental safeguards. Fostering an inclusive and open environment (at macro level), where self-advocacy is part of the curricula of young people with disabilities would build the basis of those foundational safeguards.

8.2.9 Domain 9: The cost of support

The cost of support is a crucial issue for advocacy and policy planning to implement Article 12. Not only because it implies a significant system change but also because support in the exercise of legal capacity is a fundamental right which should be available at nominal or no cost to persons with disabilities (CRPD, 2014).

Pilot projects, because of their length, size and budget, did not undertake costs analysis, except Bulgaria. However, pilot projects' reflections about their work raised several topics related to the financial constraints and the importance of long-term policy planning. First of all, they highlighted the need to include financial and non-financial benefits to draw up a complete picture. It is obvious that comparing staff involvement in a routinely and traditional guardianship model with a new and for now unframed model of supported decision-making does not really make sense.

The Bulgarian cost-benefit analysis included several useful elements to be taken into account for long-term policy planning: first of all, differentiating the costs for initial setting and the costs for running the model. This element could be refined in the future with costs for initial setting up for people who have a support network/trust relationships and for people who have no trust relationship. This information is crucial in terms of policy planning to avoid the creation of parallel systems, for those who cannot access supported decision-making immediately. Different organisations around the globe have experience with building networks, so estimations of the potential costs should be possible thanks to the experience of these organisations.

The Bulgarian analysis also used existing international instruments to measure quality of life of people with intellectual and psychosocial disabilities, which makes it an accessible tool to replicate a similar analysis by others to give evidence of the non-financial benefits and to provide conclusions in their own environment.

Last but not least, Article 12 is a fundamental right, but its advancement also relates to the community resources to which people with disabilities have access. Looking at the bigger picture helps to define priorities and plan where investment goes first. Providing self-advocacy at schools, promoting inclusive education, encouraging life in the community, employment and the accessibility of information, communication and mainstream services are all elements of the system which may help and facilitate the implementation of supported decision-making and may reduce the resources needed to set-up networks and measures of support for people who are isolated, dependent and have no or few trusted relationships. Indeed, the findings related to higher quality of life confirmed that Article 12 is interlinked with other rights of the CRPD and that investing in good public disability policies favours an environment where supported decision-making may be easier to implement.

The pilot projects faced several challenges in implementing Article 12 in practice, but they have searched for and proposed a number of ideas and innovations. Expertise has emerged on different aspects of a system of supported decision-making and how to engage with broader actors and lever drivers for change. At the same time, these achievements opened further questions and reveal research and policy gaps, which need to be addressed.

8.3 Research and policy gaps to be explored in future pilot projects

This section looks at the gaps and elements that can be included or modified in future pilot projects and that would at the same time provide further evidence-based arguments in favour of supported decision-making. The elements described focus mainly on the micro level, the work with individuals: developing and evaluating methods for support needs assessments, recording decision-making processes and defining the role of the facilitators.

8.3.1 Methods for support needs assessment and their evaluation

This research shows that several instruments to determine support needs are available and work. Indeed, no project reported about problems in relation to the instruments used. But it would be necessary to evaluate and measure the impact of the different instruments and compare their benefits in future research. Having instruments to determine support needs is an essential component of a system of supported decision-making.

Existing methods and new ones were used to map support needs. In several pilot projects staff included newly hired persons (students, volunteers, or psychologists, often without previous experience) so the pilot projects could not require extensive pre-existing knowledge or experience about specific methods. For this reason, some pilot projects decided to create a new, simple and specific instrument (NY_DOC_3, BG_DOC_1). The experience from Peru also shows that it is essential to have good instruments available at the start of the project or to include their testing and preparation within the project, to avoid losing time and energy (PE_DOC_1).

Mapping support needs has been one key element of a broader mapping of decision-makers, as the staff in most projects did not know the person before. While mapping personal characteristics, preferences, history and other elements about each individual can be essential to map a person's support needs, the projects have not looked critically at the instruments used and the information collated: were those enough or did the project staff collect unnecessary information – what are the essential and appropriate instruments?; how complex should the mapping of an individual be?; how to conduct good mapping of support needs? In some countries similar instruments inspired by Person-Centred Planning tools have been used, with small variations. But no conclusions on the use of instruments were made. Is there a common core set of instruments that should be used for all decision-makers and some additional facultative instruments, according to the complexity of the person's situation, as for example, communication support needs?

In terms of evidence base from piloting supported decision-making, it would be essential to develop adequate and effective tools. The methods used should be evaluated to be revised and fine-tuned, but also to ensure their standard use and application once the method would be scaled up from the pilot to the system. This is of utmost importance as the process of identifying support needs and supporters is in itself a safeguard. For this reason, methods need to be evaluated to provide sufficient evidence that the process itself is safeguarded.

Decision-making processes should also be recorded and monitored to provide evidence-based arguments about supported decision-making.

8.3.2 Records of decision-making process

One basic element which is missing in most projects is a system to record decisions. Not all day-to-day decisions should be recorded, as there is a risk that this would be overly bureaucratic, but for major decisions and complex decisions, records should be made. It should not only capture what types of decisions were made (if about housing, about health care) but mostly how the decision was made. A simple template like the one proposed in Annex No. 7 may be enough for such a recording, if done thoroughly. Having data on decision processes is crucial for several reasons: without elements to analyse the process of decision-making on a variety of decisions for people with different levels of disabilities, it will be difficult to argue that supported decision-making is a universal model which can work and replace substituted decision-making. Data are needed to make sure that adequate supports are available to all, including for people with complex support needs. Secondly, data are needed to provide guidance to supporters: the more examples of supported decision-making that will be available and known to others, the easier it will be for others to feel more comfortable as they will have examples to be inspired by. It is particularly important for families who are best inspired by other parents. Finally, having data would also facilitate the creation of tools, techniques and guidance to facilitate and support decisions, especially when the personal circumstances are complex (lack of preferences, contradicting preferences, risky attitude) or when the decision itself is complex (financial or health care decisions which involve a certain level of complexity) or in emergency situations or situations of serious adverse effect. At the moment too little evidence and records of decisions are available to draw any conclusion on more complex decisions.

As part of the review process, it would be good to look at: how the person and his/her supporter(s) become acquainted with the process; what decisions were problematic, for what reasons; and if a decision was then reviewed, and why. Ideally this initial phase should last at least three to five years to compile different types of decisions, both in terms of nature, complexity, timing and implementation with a sample of individuals, based on different characteristics.

While facilitators have been educating and training in an effort to reposition supporters, there is an ethical and practical question to monitoring a close relationship (parent-child in many cases). Families may feel controlled if every decision is monitored. One way to solve this issue would be to create a reporting instrument that could be used by the decision-maker and supporters (self-reporting). This report could then be shared and discussed with the decision-maker, the facilitator and the supporters, as part of common reflection about how support arrangements work and could be reviewed.

It is only by better recording real decisions made with support that the changes in the practice might be analysed and might serve as guidance for complex decisions and extreme cases.

One of the biggest challenges is who should facilitate this work and what is being facilitated. The role of facilitators is another critical element to be better defined.

8.3.3 Defining the role of the facilitator

Analysis of the pilot projects through the domains of the framework show the importance of the role of the facilitator and, at the same time, that there is confusion about facilitation work. The role of the facilitator includes complex tasks and requires further clarification. What is being facilitated? Often, several elements: the setting up of support networks, the realisation of a life plan, the process of supporting decision-making, and an educational role towards supporters. In some cases, they have also been mentoring less experienced colleagues or mediating conflicting situations (ZA_INT_1).

Facilitators learned by doing during the pilot projects and often their role has extended throughout the project as they have been frontline persons dealing with all sorts of challenges. Only the New York pilot project benefited from the lessons learned in Australia with initial training by Cher Nicholson, the main facilitator of the South-Australian projects (NY_DOC_2).

The pilot projects show that facilitators have acquired competences, experience and skills to set up agreements for supported decision-making. However, a key question remains regarding whether they should also provide support for the process of decision-making. Especially for people with more severe disabilities the fact that one person is involved could be an advantage, because of specific communication needs and the time to get to know each other. This may avoid difficulties and a potentially lower quality of support. There is also the question of the length of the collaboration with the facilitator, if he/she also provides support in decision-making.

Secondly, facilitators should also be better supported to do their work. This could take several forms: initial training, work in pairs (having a colleague observing, taking notes, giving feedback), supervision, mentoring, having the possibility to offer another kind of support when it is beyond the role of the facilitator. They should be supported by staff with different competences and knowledge, for example on alternative communication, a psychologist, a lawyer, to get the appropriate expertise and support where needed. Facilitation work should be available for all; therefore, one cannot expect the facilitator to be an expert on all sorts of issues.

Initial training is important, especially for new-comers or less experienced staff. The Bulgarian model provides an interesting example, as the organisation providing training should be registered (*register of the providers of the social service "supported decision-making")* and the training monitored (*collect data about the training programmes)* (BG_DOC_5). Such a system would allow control of the content and the frequency of the training and therefore should guarantee the quality of the training.

Thirdly, facilitators need supervision and mentoring. The pilot projects report about the necessity to cultivate and nourish a dedicated professional community of facilitators and mentors. The New York pilot project works with mentors who "*provide guidance as well as technical and emotional support to facilitators*" as defined in the project material (NY_DOC_1). Mentoring seems essential to support each other, exchange and learn from each other's endeavour and to face a large variety of situations and the complexity of decision-makers/supporters relationships. The mentors should also have an important oversight role in the development of supported decision-making, especially in the beginning (NY_DOC_1).

The analysis of the documentation and the interviews also suggest that the role of the facilitator should concentrate on building the foundation for supported decision-making: mapping and facilitating the start of the support network. It seems more adequate to separate mapping support needs and potential supporters, as it is a complex task in itself. Training and informing supporters should happen in a different setting and separately from the facilitation process. This argument is also reinforced by the observation from the New York pilot, where families reported they felt excluded, as meetings between the facilitator and the decision-maker happened without them (NY_DOC_1).

Similarly, it seems that it is also another role to assist in the supported decision-making process or in mediation if there is a complex situation. The pilot projects' experiences do not allow us to draw conclusions on whether the facilitator should or not play this role, but he/she cannot bear all the roles at once, as this raises an ethical question of impartiality and neutrality. Multidisciplinary teams with clear roles should be organised in different ways to better define the role and the limits of the facilitators' work. Several formats should be tested and adapted to the local context, the environment and the accessibility of (social) services which may play a role in the lives of individuals with disabilities. Different models of facilitation should be tested and evaluated, as there will be no one-fits-all model of facilitation.

Another element that came out of the pilot projects is that the facilitation work should concentrate on supported decision-making and preferably not include the realisation of dreams or life plans. Those are often unrealistic within the project timeframe, and it seems too ambitious to set up support networks and mechanisms for supported decision-making in parallel with the realisation of long-term goals (ZA_INT_1; PE_DOC_1; CZ_DOC_4).

All these elements are important to clarify the role of facilitators to avoid an overly ambitious and catch-all role. There is also the risk of jeopardising the quality of the process if there is no clear guidance, mentoring and additional expertise available to facilitators.

Pilot projects which developed and planned a more consolidated model suggest the creation of a new type of service, which would employ facilitators to create supported decision-making agreements, as was done in Bulgaria and Colombia. This is also why a solid definition of the role of the facilitator is a key element as it has to be a service that is accessible to all, also in remote regions, and be free of charge.

8.4 Emerging topics

Besides answers to the questions set out in the framework, five additional topics came out of the interviews and pilot projects documentation. Three topics are common to all six pilot projects. First, pilot projects are an important source of data about guardianship and about the pressure of the system to put people under guardianship. Secondly, the interviews and project documentation reveal the lack of empowerment and the absence of support to families to raise future decision-makers. Thirdly, the pilot projects highlight the challenges related to the sustainability of the pilot model of supported decision-making. Two other topics emerged from the research in some pilot projects: the importance of combining social and legal work; and the gender dimension of support also emerged from the data.

The first section looks at guardianship and the pressure of the system to put people under guardianship.

8.4.1 Guardianship: institutional pressures on families

The section draws on data from all the six projects looked at in this research (Bulgaria, Colombia, Czech Republic, New York, Peru and Zambia) and it includes mainly interviews and policy or evaluation reports:

Peru	PE_DOC_1	External evaluation report
Bulgaria	BG_INT_1	Interview with project staff
Colombia	CO_DOC_8	Academic article
Czech Republic	CZ_DOC_1	Legal analysis (Black Book)
Zambia	ZA_INT_1	Interview with project staff
New York	NY_DOC_1	Evaluation report by external evaluator

Very prominently, each pilot project throws a light on the institutional pressure to put people under guardianship, and this was the case in all the countries looked at in this research. It is striking that the same mechanisms and similar arguments in favour of guardianship, as a quasi-compulsory element of the system, can be found in very different parts of the world. All the projects gave evidence of those mechanisms, while more detailed information is available from the Czech Republic and New York where a specific activity of the project focused on understanding and describing these mechanisms.

Family members involved in the pilot projects reported about authoritative and practical arguments to put their adult children under guardianship. Belief that guardianship is necessary and the pressures to pursue guardianship are very strong. While not all family members are persuaded to secure guardianship, all conveyed that guardianship is presented as the recommended path by multiple sources. The practical arguments may relate to administrative procedures or to the protection of the person, or both (CO_DOC_8, PE_DOC_1, NY_DOC_1, CZ_DOC_1). In all countries, all these arguments are invalid from a legal perspective, but they are clearly strongly rooted in a discourse which is repeated faithfully by many professionals but also by family members.

Most influential in guiding family members toward guardianship are other parents of children with disabilities (NY_DOC_1). Doctors, paediatricians, psychiatrists, social authorities and staff, post office counter clerks (from money payments), insurance companies, health care providers staff working with people with disabilities (in services) are all the people mentioned by families who recommend guardianship (NY_DOC_1, CZ_DOC_1). There is “no other solution”; no choice or alternative is proposed to families (NY_DOC_1, CZ_DOC_1).

Families feel pressured by their environment and by the system to put their children under guardianship, although they are not always convinced it is the right thing to do. *"Other parents were not pushing me, but in conversation it’s the expectation." "Everyone thought guardianship was what we had to do. There was no other conversation about decision specific capacity; it was an all or nothing. I felt we needed to do guardianship as there were no alternatives. It was the next step” (NY_DOC_1).*

It is also crucial to note that the lack of information about what guardianship really means and its consequences are often not presented in detail, or just partially or unclearly. Many parents declared that they understood the consequences later, and the inconvenience. In all the countries, families expect that their adult child with intellectual disability will be well protected, including from civil and criminal responsibility and especially from financial abuse (CO_DOC_8, CZ_DOC_1, NY_DOC_1). The myth and the illusion that their children will be well protected is persistent, as it seems no one is really stating things clearly as they are. Once something “wrong” happens, they discover it is not the case – their children are not better protected. Sometimes they also understand slowly how much it affects the life of their child in many areas; as something they did not realise before. A mother in Peru described the contradictions of the guardianship model well: “*They would be more protected with another person, right? That protects them from being deceived, not* *cheated, not taken advantage of. But I see that you have to continue depending on someone like that, right? It's okay, but it's wrong, how do you say it? It is contradictory ... they protect your properties, your things, but you are still depending on someone*" (PE_DOC_1).

Another myth reported by families is that guardianship is a prerequisite to get access to services or to access some benefits. In the Czech Republic, parents reported that the person has to be under guardianship to get a place in an institution (CZ_DOC_1). In New York, parents said that they have been urged to proceed with guardianship to secure other decision-making arrangements—health care proxy to proceed with a surgery, or to become representative payees for some benefits (NY_DOC_1). In Colombia, sterilisation, disability pension and assets were mentioned as the three areas linked with the "need" for incapacitation procedure (CO_DOC_8). A recommendation of guardianship is often framed as necessary to be involved in medical or financial decisions, as well as to be involved in case of an emergency. Family members were also presented with frightening scenarios: "*They say scary things like what if a medical issue comes up and something needs to be done, but she doesn't understand and doesn't want the care. She could jeopardise her health. Or that someone could take advantage of her by selling her a service. The idea was guardianship would protect" (NY_DOC_1).*

Finally, many families are also being told that people with intellectual disabilities do not bother to be under guardianship as they don't understand what legal capacity means. Based on this preconceived idea, some pilot projects report that people with disabilities have been the victim of lies and manipulation to make sure that they would not try to retrieve full legal capacity, as the story of Ms Libuše in the Czech Republic shows: "*Ms Libuše works, lives in a sheltered housing, takes care of her household. She has been deprived of legal capacity for over 30 years. In 2011, she filed a motion to restore her legal capacity. In the expert opinion requested by the court, it was stated that Ms Libuše did not want to restore her legal capacity. The housing service reported that when a social worker asked her why, she replied: I do not want to move now (from the sheltered housing). Another interview showed that someone had recently spoken to her in connection with her court proceedings in the sense that if she would recover legal capacity, she would have to move out of the sheltered housing"* (CZ_DOC_1). This story is an example of manipulation of information which shows once again how embedded the pressure from the system is.

Overall, there is strong resistance to change and a desire to keep the model of guardianship: in Zambia for example, where guardianship is often informal "*other people (…) they've been somehow promoting this informal guardianship*

(…)" to keep the status quo where people are prevented from doing anything: inheriting property or running their own affairs (ZA_INT_1).

As the evaluator of the New York pilot concluded: "*Guardianship is only presented as a helpful intervention, a step to adulthood, devoid of negative consequences*" (NY_DOC_1). Pilot projects reveal that guardianship is the automatic path for people with intellectual and psychosocial disabilities, routinely proposed by professionals, anchored in preconceived ideas about people with disabilities not being able to take decisions, keeping parents and people with disabilities misinformed about its legal consequences. Participating in a project on supported decision-making was often an eye-opener for families, who for the first time maybe, heard some critical opinions on guardianship and have been offered alternatives.

Pilot projects also throw a light on the lack of support for families to empower their children with disabilities, a long-term process towards adulthood linked to the implementation of supported decision-making.

8.4.2 Lack of support for families to empower their children with disabilities and encourage their autonomy

The section draws on data from all the six projects looked at in this research (Bulgaria, Colombia, Czech Republic, New York, Peru and Zambia) and it includes mainly policy and evaluation reports:

Peru	PE_DOC_1	External evaluation report
Bulgaria	BG_DOC_3	Policy document (economic aspects, cost benefit analysis)
Colombia	CO_DOC_8	Academic article
Czech Republic	CZ_DOC_4	Evaluation of the experiences of participants in using decision-making instruments
Zambia	ZA_INT_1	Interview with project staff
New York	NY_DOC_1	Evaluation report by external evaluator

Pilot projects revealed the enormous gap between the ideal of supported decision-making and the reality of families who are not prepared nor accompanied on their journey to raise and empower their children with disabilities. They lack support to train them to acquire decision-making skills and be more autonomous.

Pilot projects were realised in countries where the level of services available to people with disabilities is very different, and also within a pilot project, the socio-economic level of each family and decision-maker involved may have been very different, as described in Chapter 6. Therefore, it is difficult to make some comparisons about opportunities for exercising self-determination and the support available for families. But the general trend which can be observed is that people lack opportunities and experiences in decision-making.

In all the pilot projects, but specifically in Peru and Colombia, the project reports clearly state that people with intellectual disabilities have no autonomy in decision-making in their daily routine (clothing, money management, daily activities…), are not involved in decisions, and their opinions are not taken into account. They are seen and treated as children also in their adult age. They are viewed by the families through their "deficits": "*I don't let him do anything, everything looks bad after him and he isn't capable of doing things here at home.*" (quotation by the mother of a participant in CO_DOC_8). "(…) *families, you know they still feel they have to make decisions on behalf and those people cannot make decisions or cannot be supported to make decisions, all the choices are being imposed on them" (*ZA_INT_1).

At the same time, families are very much aware of the advantages of being more autonomous but the lack of time, knowledge and support to develop skills with their children and the exhaustion of the primary carers are all barriers which cumulate in front of this task. *"I would have to teach him to cook (...) He is very intelligent and could learn, but the thing is that (...)I don't have time to teach him (...) In order for him to learn to cook, I would have to teach him the rest of my life*" (PE_DOC_1).

Families are not supported to raise their children with disabilities as future adults, as they lack expectations and future plans for them (CO_DOC_8). Families themselves experience exclusion and lose network resources, which can lead to the fact that the person with a disability is even more dependent on his/her family members/carers. The lack of community interaction, work opportunities and the lack of social relationships, friendships and opportunities to meet new people are all barriers to building the autonomy of people with intellectual and psychosocial disabilities.

The lack of investment in building autonomy and independence has a very negative influence on the self-esteem and self-representation of people with disabilities. The pilot projects provided clear evidence that even over a short period of time the support provided to people with disabilities and their families through the activities of the pilot projects has had an impact on the necessary skills and self-esteem of the participants, which form the base of competences to make decisions. In short, the project created a space for self-development and self-determination of their adult children with disabilities.

Families have also learned while being part of the pilot projects. A mother involved in the Peruvian pilot project described her experience: "*I looked at her as still a child, a little girl, and what the workshop has helped with is to raise awareness that she is an adult and that she has her duties and rights as a citizen, that she can be empowered and have… a better quality of life, right?*" (PE_DOC_1).

Families indeed changed attitudes, accepted that their children take on responsibilities, took positive views of their personal life plans, and they now understand the importance of taking decisions, accepting and recognising the role of support networks (CO_DOC_8): "*With this project I have learned the importance of him making decisions, that he does what he likes not what is his turn, it is necessary to guide him and to give him a little bit of help, so that he understands."*

Family members, who were part of pilot projects, are more able to step back and allow the decision-maker to make more decisions, they give space to the decision-maker for having a voice and they communicate more. The project has created opportunities for important conversations and therefore it reduces family members' fears about the future. Parents are reflecting these positive changes and they are happy with: *"Progress in that I'm taking steps back. I'm transitioning." "Definitely…it opened things up a bit for all of us, thinking about the future together. More moving forward which is good for him and for us"* (NY_DOC_1).

The pilot projects gave a strong indication of the crucial role families play in creating a system of supported decision-making, because there are preparing children for their future but they are also chosen by people with disabilities as their supporters. To achieve full legal capacity of people with disabilities, whatever the level of support that is required by individuals, children with disabilities need to be raised as future adults in their family environment. At the same time, the pilot projects also show how massive the need for guidance is and the need for creating a supportive environment to raise their children with disabilities as future adults interacting with the society. As the project coordinator for Peru and a mother of young boy with Down syndrome concluded: *"It's more than autonomy, the capacity of moving around in the community. Feeling safe. Things that are related to any decision of daily activities like going to the shops and buying or having a bank account; or just being able to tell their families that they want their rights to be respected like the right to privacy"* (PE_INT_1).

A corollary to the important role played by families is that support, in general, but also support for decision-making raise the gender dimension of an unbalanced role of mothers and women in this process towards autonomy.

8.4.3 Providing support for decision-making – a gender issue?

The section draws on data from three projects looked at in this research (Colombia, Czech Republic, and Peru) and it includes mainly evaluation reports:

Peru	PE_INT_1	Interview with project staff
	PE_DOC_1	External evaluation report
Colombia	CO_DOC_8	Academic article
Czech Republic	CZ_DOC_1	Legal analysis (Black Book)
	CZ_DOC_4	Evaluation of the experiences of participants in using decision-making instruments

Both the Peruvian and the Colombian pilot project reveal the massive female presence in the projects: all primary carers are women, most of the time mothers (PE_DOC_1).

While the role of women as carers is something that has been studied elsewhere by academics, it was somehow unexpected to be confronted with the gender dimension through the question of legal capacity and supported decision-making.

The pilot projects throw a light on the existing pressure on women, because they take the responsibility as carer but also as supporter, to increase the autonomy and the skills of their sons and daughters with disabilities. "*The mothers or the sisters of the persons with intellectual disabilities are the ones who make the decisions. And they are then responsible for the good decisions or the bad decisions regarding their family member with a disability. (…) Are you really gonna let him go to shopping on his own? What if he gets lost? (…) so if the mothers are willing to make changes, they have a lot of pressure. Not to make them*" (PE_INT_1).

Being part of the pilot project also helped the primary carer, a woman, to feel more empowered to fight back against their own families, when they push for more autonomy, against the opinion of other family members. In almost all cases, the primary caregiver is indeed the fundamental pillar of the support network, a role that several of them play with little collaboration from other people. They experienced many years of much effort and loneliness (PE_DOC_1).

To look at the relevance of this topic in other countries, the documents including interviews with families were scanned to see who the family members responding to the questions are. All the family members interviewed in an article from Colombia and in the Czech Republic about the pilot project are mothers or other female family members (CO_DOC_8) (CZ_DOC_1 and CZ_DOC_4). The report from New York is gender neutral (parent, guardian or potential guardian), so it is not possible to identify this issue. However, given the knowledge about the role of women as carers, it seems important to keep it in mind when thinking about empowerment and support for decision-making, that information, practice guidance and training content may need to be different or adapted for mothers and for fathers, to avoid gender discrimination and an unbalanced role.

Besides the empowerment process of people with disabilities and their families, pilot projects have combined social and legal work to design innovative proposals and recommendations for a system of supported decision-making.

8.4.4 Linking social and legal work: how to utilise social work for a legal reform?

The section draws on data from five projects looked at in this research (Colombia, Czech Republic, and Peru) and it includes primarily interviews:

Peru	PE_INT_1	Interview with project staff
Bulgaria	BG_INT_1	Interview with project staff
Colombia	CO_INT_1	Interview with project staff
Czech Republic	CZ_INT_1	Interview with project staff
	CZ_DOC_5	Policy document (legal aspects)
New York	NY_DOC_3	Academic article

In most projects and as a strong component of the Czech, Bulgarian and Colombian projects, social and legal work have been combined and have nourished each other.

One of the biggest challenges for the pilot projects, and for reforming the system in the light of Article 12, is to create synergies between the social work, and the legal work, guaranteeing that what has been done thanks to social work can be legally validated and recognised by others, linking both the micro level with the macro level.

To achieve this goal, the Colombian partners created a strategic alliance with the Programme Action for Equality and Social Inclusion (PAIS) of the University of the Andes, whose lawyers were helping with the legal elements (CO_INT_1). The University País programme also created a virtual course, focused on legal capacity, which is now part of a mandatory training platform for judges and notaries (CO_INT_1).

In New York, the Project Director, a retired judge who reviewed guardianship petitions while on the bench, is very attentive about the way the facilitation process (and the resulting supported decision-making agreement) is used in litigation: "*it had to be carefully structured in a way that demonstrated the integrity of the decision-making process to judges—as well as to stakeholders more broadly*" (NY_DOC_3).

In the Czech Republic, Bulgaria and New York, lawyers have been involved in the preparation of supported decision-making agreements or in the process of restoration of legal capacity for people under guardianship to provide legal argumentation for the approval of supported decision-making agreements or for recovering full legal capacity (BG_INT_1, CZ_DOC_4, NY_DOC_3).

In some cases, pilot projects demonstrated the possibility to reduce the number of support measures attributed by court decisions, allowing for example out-of-court agreements of support.

The collaboration and combination of expertise is assessed by pilot project leaders as a positive and fruitful element. At the same time, it is very difficult to measure the impact of this combination of legal and social work on the system changes as they are not always measurable and they have not been evaluated. In the Czech Republic, the lawyer involved in the work described how they have tried to influence the system and to a certain extent have been successful. "*I think we managed to bring the issue to the attention of the judiciary, … it got on the agenda of the ombudswoman, ... the fact that they involved us in the training of public guardians .... I think that was very significant.*" (CZ_INT_1). In Colombia, the pilot project ended while the new law was adopted: "*Parallel to the construction of the bill, the organisations that are part of this project, became part of the construction of this bill. Then, elements for the construction of that bill came out from the outputs of this pilot, of this research. Also the bill retains the components that our guide about alternatives has, because the two things went hand in hand*". (CO_INT_1). In Bulgaria, the project director even states, that "*I would say that the draft law is really representing most of the ideas that are coming from the pilot programme itself. The draft law was very much influenced by it. But, really, I want to underline that especially the final one that was introduced in the Parliament is not 100% the things that we want, because at the end it was not us to finalise the provisions and the proposal.*" (BG_INT_1). Finally, in Peru, the influence of the pilot on the new law passed at the end of 2018 is less evident. The new law removes plenary guardianship *(interdiccion*), introduces new alternatives, but still includes a form of limited guardianship (*curatela*). While the organisation leading the pilot project was involved with the Ministry of Justice for four years in the consultation process for the change of the Civil Code, the political changes did not allow a clear follow-up of the changes of the draft (PE_INT_1). Bu

Pilot projects aimed finally to change the legislation but also the whole system, thus improving the status of people with intellectual and psychosocial disabilities with their new legal status. This is why they invested a quite significant amount of work in advocacy and community outreach to find ways to make the pilot projects sustainable.

8.4.5 Challenges to make pilot projects sustainable

The section draws on data from all the projects looked at in this research (Peru, Bulgaria, Colombia, Czech Republic, Peru and New York) and it includes primarily interviews and evaluation reports:

Peru	PE_INT_1	Interview with project staff
	PE_DOC_1	External evaluation report
Bulgaria	BG_INT_1	Interview with project staff
Colombia	CO_INT_1	Interview with project staff
Czech Republic	CZ_INT_1	Interview with project staff
	CZ_DOC_5	Policy document (legal aspects)
New York	NY_DOC_1	Evaluation report
	NY_DOC_3	Academic article

All the pilot projects faced two main challenges: planning long-term changes and ensuring the sustainability of the model they have been piloting. Therefore, they tried to involve a larger community through advocacy work, partnership and networking. While the activities of the projects show it is a necessary step to achieve more profound changes, it is also a difficult task, as project leaders described. The variety of ideas and techniques pilot projects have used offers a large palette of experiences and inspiration for future projects. Each project pursued several strategies within one project. Some highlights are described in the following paragraphs to illustrate this topic.

The Bulgarian project, which is among the longest ones, developed a two-fold outreach strategy: 1. "*to find people from different professional groups to make them close to the pilot programmes so they can see first-hand the outcomes, not just to read papers and analysis*". 2. "*to find and headhunt – it is not a politically correct term but it is the right term – people open to listening and discussing and try to convince them and after that to make them active as advocates*" in those professional groups. In practice, it means to find a doctor to talk to the health care committee and a law professor to talk to the legal community. It is described by the project director as a long process but successful as they managed to make these people their allies (BG_INT_1).

In Colombia, they used online material as a strategic development tool to reach out to people on the topic of legal capacity: they designed a virtual course for facilitators, thanks to their experience, to train organisations of people with disabilities in what they had found and learned in the first phase. The idea was to transfer knowledge outside Bogota through a "train the trainers" programme to create a second wave of pilots and implement the methodology, in their own organisations. They trained 36 persons from different organisations thanks to the virtual course. Some of the participants then run pilots in their turn (CO_INT_1).

In the Czech Republic, "learning communities" met regularly over several years to exchange about their progresses with supported decision-making – people from social services, lawyers, families and people with disabilities were involved. Meetings provided space for sharing experiences, problem solving and mutual reflection on how to move on particular cases. This gave the project team a bigger picture of the situation across the country and more examples of concrete individual cases to work with. Learning communities represent a significant tool to replicate and extend the practice outside of project partners and make the model sustainable (CZ_INT_1).

In Zambia, the project team managed to create a large stake-holders group through the National Advisory Group bringing together: policy-makers, including the Ministry of Local Development, service providers for people with intellectual and psychosocial disabilities, families, and also the specialist hospital that deals with persons with mental health issues (ZA_INT_1). They replicated this idea at local level by bringing together services providers from local communities and by creating "*a design committee: one social worker, one family member, an influential DPO, a pastor from one of the Church councils and also a traditional leader. (...) and they are very confident with the local people they are living with them in those communities*" (ZA_INT_1). Members of the committees have been familiarised and trained with legal capacity and supported decision-making concepts. The project leader reflected positively on their capacity to mobilise various stake-holders to discuss mental health issues and the challenges that people with intellectual and psychosocial disabilities are facing, stigma and discrimination (ZA_INT_1).

In Peru, the sustainability strategy focused on municipality. But "*having the municipalities engaged with and committed to the goal of our project, has been a challenge*", summarised the project Director. Municipal organisations were poorly involved, their representatives have attended meetings irregularly, they were passive and not proactive during the whole project. The evaluation report also points out some of their critics, especially the fact that only people with mild and moderate intellectual disabilities were involved and that autonomy is not a new topic for them. On the other hand, they valued the objective of the project, the methodology and ideas related to alternatives to guardianship (PE_DOC_1). The engagement of municipalities should have been better prepared and better explained, to make sure they would not only be passive observers. The evaluator suggests that the lack of ready-to-use material and guidelines may explain that external partners did not engage more (PE_DOC_1).

The New York pilot planned to work with volunteers' facilitators – mainly students from graduated programmes at university as part of their clinical or fieldwork requirements. Establishing a sustainable volunteers pool has proven to be very challenging (NY_DOC_1). It was seen by the project leaders as a key element for long-term sustainability and presented many advantages in their views, including from a financial perspective and because of the quality of their education. However, a long list of barriers and practical problems with different schools in New York made this, which seems to be a good idea, a difficult task to realise in practice (NY_DOC_3). Also, students faced competing priorities finding time for the project. After many trials and efforts by committed parties, the project may have found a way to incorporate facilitation into the placement requirements for special education students, rather than social work students (NY_DOC_1, NY_DOC_3). A volunteers' pool is an essential element of the model – as they work as facilitators to set up agreements of supported decision-making.

The experience of pilot projects to make it sustainable reflects the complexity, the diversity of actions and stake-holders to interact with and the amount of work needed to make a supported decision-making system a reality.

Chapters 7 and 8 described the findings, the accomplishments, the challenges and the gaps in advancing the implementation of Article 12 by pilot projects. The following and final chapter discusses in more detail these findings and their implication for future pilot projects as well as cultural and policy changes to achieve the implementation of Article 12.

9 Discussion and Conclusions

This dissertation sets out to explore the implementation of Article 12 CRPD by pilot projects from the practical, legal and policy levels. Research related to Article 12 showed that the notions of universal legal capacity and supported decision-making are not yet clearly defined. Scholars also pointed out that there is a lack of a quality evidence base of supported decision-making, both in terms of processes and outcomes. Post-CRPD developments include several legal reforms, several new programmes, but there is a lack of comprehensive implementation of Article 12 (CRPD, 2014; ENNHRI, 2020). This dissertation aimed to address this gap and looked for answers by exploring the aims, methodology, outcomes in six pilot projects seeking to implement supported decision-making in different parts of the world but not yet formally evaluated. To analyse how these pilot projects can help us understand how to operationalise Article 12, nine domains related to the practical implementation of Article 12 were scrutinised. A number of advancements were achieved in the various countries as a result of the pilot projects. Some progress and accomplishments in law reforms and implementation, in producing and delivering training courses or material for supporters and decision-makers, also in developing advocacy strategies and networks for reforms, and in campaigning about supported decision-making were identified. Several challenges – resistance to changes, gaps in policy, lack of infrastructure – are also reported by the pilot projects. Eventually, many questions, especially regarding support in hard cases or "interpretive" supports, remained unanswered. This chapter discusses the lessons and the barriers in the implementation of Article 12 together with the limitations of the thesis and formulates recommendations for future pilot projects and for research.

9.1 Lessons learnt from the pilot projects

The pilot projects showed that many aspects of supported decision-making are feasible and have a positive impact. One clear message from the pilot projects is that it is worth it. This section summarises and discusses the lessons learnt from the pilot studies in terms of both outcomes, methods and processes.

9.1.1 Outcomes of the pilot projects

The pilot projects confirmed that people involved in the projects are benefiting from it; the longer the project was, the more benefits there were. All the interviews and documents related to the pilot projects show that this is the right path to take – it brings positive effects in the life of people with disabilities and also of their supporters. The changes may have been rather small, certain personal circumstances may have been very difficult but the process brought positive elements. Those elements can be summarised for all the pilot projects in three main aspects: 1) people participating were more empowered and more autonomous as they learned more skills, and they increased their participation in decision-making (even if only in everyday decisions); 2) it is a positive learning process for people with disabilities, their supporters and family members but also for the staff involved in the projects – everybody has learned and changed views and attitudes; 3) it has great potential to improve the quality of life of people with disabilities, as satisfaction is higher. Data are too scarce to measure how strong the impact on the quality of life of pilot participants is, but the analysis done in Bulgaria confirmed the hypothesis that supported decision-making impacts on the quality of life thanks to better respect for human rights, more opportunities for independent living and better social inclusion of people with psychosocial and intellectual disabilities. The pilot projects concluded that their work was worthwhile because they brought a new perspective: people who have been through the process of designing a model of supported decision-making think differently. It set the path for a change of model.

Parallel to these positive outcomes a growing amount of information, material and training resources was produced and disseminated. Information and training material were designed for decision-makers and their supporters, law professionals (judges, lawyers, notaries), social workers and facilitators, as well as policy makers. A growing body of experts has been built.

The experience of the pilot projects, with all their limitations, confirms the view that supported decision-making is in itself beneficial, as deciding for oneself has an intrinsic value: it preserves the personal autonomy of people (Devi, 2013).

9.1.2 Opportunity to grow and develop decision-making skills

Another positive outcome of pilot projects was that they laid down the foundation for people with disabilities to control their own life, by providing opportunities to grow in the sense described by Amita Dhanda (Dhanda, 2007), and have their legal capacity recognised. This opportunity to grow described in paragraph 24 of General Comment No. 1 is central to legal capacity: *"One of the aims of support in the exercise of legal capacity is to build the confidence and skills of persons with disabilities so that they can exercise their legal capacity with less support in the future, if they so wish."* (CRPD, 2014). Article 12 counts with progressive control over one's life (including through training, skills development), with more or less support needed by the decision-maker (CRPD, 2014). The notion of evolving decision-making skills appeared to be central for the realisation of Article 12 in the work of pilot projects. Developing decision-making skills is a separate action, but it contributes to the exercise of legal capacity. The question is how to integrate the evolution of decision-making skills in the context of the exercise of legal capacity. It should be looked at in the process of setting supported decision-making (where relevant, with concrete measures to develop decision-making skills), in monitoring its implementation and reviewing the arrangements in place, taking into account the experience and the skills acquired. People with disabilities should have the possibility to develop their decision-making skills in different settings. This includes opportunities in the families, but also opportunities for self-advocacy and empowerment already for young people –at school and then through training courses, educational activities and participation in services and settings for adults. Having choices – even smaller ones related to food or clothing – and taking decisions built this necessary experience of decision-making.

Opportunities to grow and develop as well as self-realisation are the foundation of legal capacity for all (Quinn, 2011; Dhanda, 2007). The pilot projects have, at least on a very small scale, created some of those opportunities, by expanding personal networks.

9.1.3 Reducing pressure on families and expanding the community network

Pilot projects showed that the access to support is fragile and precarious, as it mainly relies on families. They pointed out the huge pressure on families, who are often the only available support, or the main source of support, including for decision-making. Families are essential for building autonomy, creating and maintaining networks and relations. By throwing a light on women and families, the pilot projects provided a partial answer to the call for data on supporters made by some scholars like Kohn, as they provide evidence about the massive role of families which did not yet receive particular attention in the literature.

The pilot projects highlighted that substantial resources and support are needed for both people with disabilities and their families or supporters. It requires families being adequately supported to enable their family member with a disability to have more autonomy. It means for example in-family support services for people with disabilities, with staff members who are trained in person-centred methods and in community work, and at the same time, have facilitation skills. The pilot projects show that both are intrinsically linked, as there cannot be supported decision-making if there is no push towards autonomy. If there is no investment in programmes for families, in schools and free-time activities to enable decision making skills and shape autonomy of children with disabilities from an early age, there is the risk that supported decision-making would remain only declaratory and empty of content. This would amount to substituted decision-making or best interests decisions in practice (ENNHRI, 2020).

Similarly, where people with disabilities have no family ties (because of institutionalisation or because they don't want them for different reasons) their autonomy should be supported by adequate programmes.

As described in the evaluation report of the New York project, extending the supporter role beyond relatives would:

- allow them to move on or "retire" from their role as supporters;
- broaden access to supported decision-making for people who may not have involved family or who are socially isolated; and
- reduce vulnerability to abuse, neglect and exploitation by having wider social networks. (Pell, 2019)

At the same time, the pilot projects demonstrated on a small scale the capacity and expertise needed to develop support for legal capacity with people who have lived in institutions and/or who are living in a very isolated way.

Academic and policy papers discuss the importance of support in the community or natural support when talking about Article 12. And by contrast the situation of isolated people or people with no social ties is pointed out as a separate problem. But support in the community often equals support by families or relatives. Most decision-makers experience a rather poor and limited network, thus making this contrast subtler.

Creating a favourable environment for supported decision-making means to reinforce ties with the person's community and environment. The General Comment No. 1 notes that "*States parties must recognise the social networks and naturally occurring community support of persons with disabilities as key to supported decision-making*. But it needs much more that recognition. Pilot projects illustrate that it needs intense work to ensure that the community will provide support to persons with disabilities. The pilot projects show the importance to prepare the community to provide people with disabilities their part of support to exercise legal capacity.

By working with Article 19, pilot projects confirm the strong connections between supported decision-making and community living. These links take on even greater importance in low-income countries, where access to professional supports may be more restricted, but also after the COVID-19 pandemic, the social and economic impact of which may have affected disability policies in the long-term because of competing priorities.

The interdependence of Article 12 and Article 19 and their strong ties have strongly emerged in the pilot projects, reflecting the complexity of supported decision-making.

9.1.4 Scaling up: the importance of building alliances and system level partnership

With different levels of development and successes, pilot projects have initiated partnerships, alliances and networks with different partners. Alliances helped to scale-up the pilot projects ideas, to advance policy and legal advocacy work as well as to expand the use of training tools and material. Learning communities in the Czech Republic, the legal network with universities in Colombia, or alliances with different professional groups in Bulgaria are examples of successful activities to scale-up pilot projects results. Sharing information, success stories, training material, and finding allies have proven to comprise an essential component of the pilot projects and an accomplishment.

However, pilot projects have not been able to test several aspects of a system of supported decision-making but not all aspects, especially those at mezzo and macro level. There is a real need to scale up pilot projects at one relevant administrative level (municipal, local or national) to involve all the actors in the piloting, not only by providing them with information. Planning a pilot at system level may be very challenging as several projects reported difficulties in dialoguing with the authorities. This obviously requires political will and decisions in the process, but strong arguments in favour of such a step to avoid lack of preparation could be put forward. Pilot projects have been able to design elements for a system change. It would therefore be essential to test all elements of the system as a whole, involving local authorities, courts, social services and third parties (banks, doctors, etc.). It would prevent mistakes from being made, and would allow good planning of the transition from the “old” to the “new” system. Lessons learned from a pilot at system level would provide an additional layer of experience, would allow a good preparation of the different groups of people to those changes (in terms of training and practice guidance) and would also allow more precise budgeting of the reform.

Such a scaling-up process would also allow testing of the safeguards, including procedural safeguards, and monitoring that they are reliable, and that they contribute to the respect of the rights, will and preferences of people with disabilities.

The experiences of those and the lessons learned reveal the gap between the theoretical discussions around the meaning of Article 12 and its implementation in practice. On the other hand, the pilot projects throw a light on a number of important issues, which have not yet been central to the academic discourse. This said, the pilot projects also confirmed the significance of universal legal capacity for people with disabilities and the numerous barriers their initiators faced in implementing Article 12 CRPD.

9.2 Challenges and barriers to the implementation of Article 12

The pilot projects indicated four main challenges and barriers to the implementation of Article 12: institutional resistance to change; the lack of coordination between practice, programmes, policy and law reform; the unfilled gaps and the lack of supported decision-making infrastructure for successful implementation.

9.2.1 Institutional resistance to change

The analysis of pilot projects illustrated how deeply the notions of guardianship and substituted decision-making are accepted and rooted in the minds of most people and how difficult it is to offer a credible alternative. The pilot projects faced difficulties in finding volunteers to enter their programmes (all free of charge), one of the frequent reasons being the lack of information and distrust towards something new and the fact that supported decision-making was seen as an idealistic, not to say unrealistic idea.

The pilot projects show that many families and workers in the disability field consider guardianship as a pre-requisite, a “normal” step in the life of people with intellectual and psychosocial disabilities. Guardianship has hardly been questioned because of the persistence of the myth of protection, the lack of information about its negative effects, the lack of awareness of human rights abuses and the institutional pressure by the system to put people under guardianship.

The pilot projects have represented a call for change as they cast a light on substituted decision-making models and the absence of respect for the rights of people with disabilities. Institutional resistance to change, for example in health care, in the justice system, in financial institutions and in different administrations – is difficult to push back. So far, the institutional structures of countries where pilot projects have been implemented have not “shifted in thinking” to adopt a new approach and be able to consider legal capacity of people with disabilities from a supported decision-making perspective.

The myth of protection relates to Article 12, but it goes far beyond this article. It relates to the CRPD as a whole and the rights of people with disabilities in general – the issue of legal capacity concentrating a number of myths and preconceived ideas about people with intellectual and psychosocial disabilities (e.g.: eternal children, not able to take decisions for the first group, dangerous to let them take decisions for the second). Legal capacity reforms call for awareness-raising about capabilities, autonomy but also the diversity of people with disabilities, ensuring that each person can receive an individualised support scheme.

9.2.2 Coordinating practice, programmes policy and law reform

Pilot projects on supported decision-making changed practice and built new programmes in some countries thanks to newly developed new tools for support needs evaluation, facilitation and community networking. Law reforms happened in some countries – Peru and Colombia experienced substantial reforms while other countries, which includes legal recognition of support. Law reform is essential to guarantee the rights of people with disabilities and that their support arrangements are recognised and their decisions honoured. It also guarantees that safeguards are in place. At the same time, third parties need legal security for their transactions.

However, findings from the pilot projects highlighted the fact that practice, programmes and law reform should progress simultaneously. The Bulgarian case provided an example of a pilot project which has grown into a large-scale and well-functioning programme. However, there is always the danger that a person can and will still be deprived of his or her legal capacity, as supported decision-making arrangements have not been legally recognised so far. The Czech Republic is the perfect counter example where the law has been changed on paper but the system was never prepared for that change: no policy and programme have been put in place – so guardianship remains the main answer to legal capacity issues although alternatives exist (from 2014 to 2020 only 339 agreements on supported decision-making were approved[92] compared to the stable number of 36,000 persons under partial guardianship) (Brozova Rittichová and Redlichová, 2011).

Having the guarantee of legal recognition would be a definitive outcome and it would also attract more people who do not believe in it as it is not in the law. Many families want the guarantee that further legislation will exist (Pell, 2019).

Unfortunately, there are very few examples of law reforms that were initiated or influenced by the pilot projects, with the notable exception of Colombia and to a certain extent Peru.

When a law reform has passed, policy and programmes should be designed and delivered to get institutional changes. Similarly, where pilot projects have turned into a programme, the law is needed to guarantee the validity of their agreements. Scaling-up pilot projects is not sufficient to achieve a systemic change. The public administration should be in charge of preparing and implementing the law, by having a policy and training strategy and programmes to deliver a tested practice by organisations which have sufficient capacity for it.

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[92] Statistics of the Czech Ministry of Justice are available on: https://www.justice.cz/web/msp/opatrovnicka-agenda (last accessed 27/10/2021)

With the publication of the General Comment on Article 12, the Committee turned down the path of having parallel systems and closed the discussion about the "compromise" left open in Article 12 not explicitly prohibiting substituted decision-making. This is seen as very problematic and it may slow down reforms, as co-existence of both systems is needed to find viable alternatives, simply for the reason that there are many unanswered questions about Article 12 implementation. Finding those alternatives to substituted decision-making takes time: law reforms should be accompanied by policy, programmes and training to change the mind-set of all relevant groups in society. There appears to be a disconnect between the law reform planning and the CRPD Committee view, which is undermining its authority (Craigie et al., 2019). The Committee is indeed expected to offer guidance on the implementation of the CRPD, rather than a position without compromise.

One of the frequent arguments for having parallel systems is the fact that many questions about how a system of supported decision-making should work are still unanswered.

9.2.3 Unfilled gaps

Pilot projects have developed expertise, but a number of gaps still need to be addressed with priority to increase knowledge and the availability of good practice examples. First of all, as described in previous chapters, there is a lack of proven and tested support needs assessment tools and no guidance on how these tools should be used. Without proper evaluation of the methods, it is impossible to discuss wherever they comply with the non-discriminatory indicators of support needs required in the provision of support to exercise legal capacity (CRPD, 2014).

Secondly, there is no functioning system of supported decision-making for people with high support needs. Limited experience with this group of people and the lack of instruments to recognise the specific arrangements for people with high support limit the experience and the practice of pilot projects to people with lesser needs. More piloting work and research in the field of "best interpretation of will and preferences" or interpretative supports are needed. Guidance for the process of interpretation, validation of the process of interpretation and its legal recognition as well as safeguards for specific decisions (e.g.: health care treatment), including ways to challenge the decisions are all questions to which answers are needed.

This step would also help in refining the definitions and the differences between supported and substituted decision-making – and to what extent interpretation of will and preferences can be supported decision-making and where a decision would be considered substituted decision-making. Similarly, there are no experience and guidance available for extreme cases (imminent risk of harm or self-harm / situations of serious adverse effect).

Thirdly, the notion of reasonable accommodation has not really been used nor explored yet in exercising legal capacity. Clear guidance on the duty to accommodate should be defined to set standards for what is reasonable and what is an undue burden. Until now, this policy gap practically does not allow people with disabilities to use their right to reasonable accommodation in exercising legal capacity. The notion of accessibility in the context of legal capacity should also be explored to facilitate the access to information related to the exercise of legal capacity (e.g._ finances, assets, heritage or medical information) and to services open to the public (e.g.: legal and financial advice) To combat institutional resistances and promote the general use of the accessibility duty and reasonable accommodations, clear policy and guidance are needed.

9.2.4 The lack of supported decision-making infrastructure for successful implementation

Findings from the pilot study highlighted a number of key questions related to the universality and accessibility of the model(s). The pilot projects pointed out the lack of community infrastructures which are needed to ensure the development of supported decision-making. This also relates to the questions of resources available. Sufficient infrastructure is needed:

1) for families to have the resources to enhance autonomy
2) to provide enough self-advocacy and empowerment opportunities for decision-makers in the community; to ensure their participation at schools, in services…
3) to access facilitation – how to ensure that it is a universal and accessible service for all, how to ensure sufficient expertise in remote areas? How to provide quality facilitation service for people with high support needs?
4) to offer assistance to the facilitators as well as the decision-maker and his supporters: information, advice, monitoring and mediation role
5) to ensure access to a panel of support options (e.g. communication support, peer support), for instance informal and formal supports. How to ensure individualised features?
6) to provide training to all the necessary sectors (health care providers, justice staff, lawyers, social workers…)
7) to make accessible mainstream instruments which have not been envisaged as support in decision-making before

The model providing *"various support options which give primacy to a person's will and preferences and respect human rights norms"* as described in the General Comment will require creativity and flexibility to make facilitation services available everywhere also in remote areas and for people with high support needs.

The risk of providing supported decision-making as a programme is a real danger, which some pilot projects have already experienced, by providing facilitation for supported decision-making within the capacity of the organisation(s), with no systemic change followed.

This topic was raised by Tony Phillips, a self-advocate from a US organisation in his remarks at the United Nations Conference of State Parties to the CRPD in June 2017): *"[I]t can't be just another service. And that's what going to happen if it's something that only agencies do. (…)Once I have my agreement in place, and once my supporters are on the same page, it's mine to do what I want with. I don't have to depend on the program to do what I want to do the same way I have to depend on the agencies. And that's important. That's independence."* (Both Glen, 2020).

Developing community infrastructure is essential to ensure that supported decision-making can exist at the system level, and not just as a programme.

The analysis of pilot projects suggests a list of topics to be further explored by academic research, for law and policy reforms and also for further pilot projects.

9.3 Implications for theory and law

To build on the achievements identified to date and to better confront persistent challenges, further policy analysis and academic research are needed to positively contribute to the implementation of Article 12. The implications for research as well as law and policy reforms are presented at the three levels of the model (the micro, mezzo and macro levels).

9.3.1 Micro level

Research should concentrate on the development of methods to assess support needs specific to supported decision-making and on the evaluation of these methods. The literature offers no information about what methods should be used, as academics have rather looked at why current methods are not in compliance with Article 12 (Dhanda, 2007; Devi, Bickenbach and Stucki, 2011; Flynn, Arstein-Kerslake, 2014a, 2014b; Browning, Bigby and Douglas, 2014; Committee, 2014; Gooding, 2015). No concrete proposal for new forms of assessment has emerged yet. Only the model by Bach and Kerzner proposes to shift from the concept of mental capacity to the concept of decision-making capability to maximise the autonomy of people with disabilities (Bach and Kezner, 2010). However, the model has been criticised for not complying with the non-discriminatory indicators of support needs as it runs the risk of discriminating against persons with disabilities (Flynn, Arstein-Kerslake, 2014a; Gooding, 2015). The involvement of academics could be sought to help the development of tools, measure their performance and identify best practices. Academic research may also provide critical information and assessments of the methods. Evaluation would provide elements for the improvement of existing methods and could guarantee that methods have been designed to include people with high support needs. In addition, comparative studies between methods would provide resources for other countries where there is no method to assess support needs and encourage adaptation from existing models.

Academic research could usefully concentrate on longitudinal studies to follow cohorts of people with supported decision-making arrangements, which would evaluate the long-term impact of supported decision-making schemes. It would allow building knowledge and giving meaningful content to the notion of opportunities to grow and skills for decision-making. Following the decision-making processes of individuals on his/her decisions over time, and their outcomes would provide data and analysis on how wishes and preferences are respected and may be interpreted. It would also provide elements to assess the quality of the decisions made. This would provide the empirical data needed to evaluate processes and outcomes of supported decision-making and the utilisation of supported decision-making, i.e., who is using supported decision-making, who are the supporters, with what frequency arrangements are used and for which decisions (Kohn, Blumenthal and Campbell, 2013).

Ensuring the inclusion of people with high support needs would be essential to promote the development of and evaluate the implementation of arrangements for supported decision-making for this group of people. Finally, these data could potentially provide a better understanding and definition of what are “interpretative” supports for people with high support needs (best interpretation of will and preferences). As it was suggested by Mansell et al., 2007, with regard to deinstitutionalisation and the development of community living, if we can get a system in place that works for people with the most severe disabilities then implementing supported decision-making for everyone else will be easier.

9.3.2 Mezzo level

The acceptance of their duties by third parties (e.g.: banks, doctors) is an important step in the process of decision-making, especially for the implementation of a decision. Further projects and research should assess interactions with third parties and provide guidance: what processes of verification are available, how verification works or does not work in practice, how third parties accept and respect the work of the supporter and the decisions of the decision-maker, how the duty to accommodate is effective, what accommodation is offered. The evaluation should take into account the perspective of the decision-makers, of the supporters and of the third parties. For a scaling-up phase, it should guide on measures to facilitate the implementation of supported decision-making arrangements from the perspective of third parties – information and educational material, training, both in terms of legal issues (legal capacity of people with disabilities, supported decision-making arrangements) and in terms of disability aspects (introduction to the social model, communication aspects). It would allow building content for third party obligations and limits, together with the future analysis of any available case-law (absence of recognition of a supported decision-making arrangement, denial of reasonable accommodation).

The areas of contract law and reasonable accommodation in the exercise of legal capacity could be a useful topic for legal and policy research, as there are so far almost no concrete ideas or practice.

9.3.3 Macro level:

The macro-level offers several opportunities for policy analysis and academic research. First of all, new models could include costs-benefits analysis which includes a focus on broader quality of life. The models used in the Bulgarian pilot projects were internationally recognised instruments (Personal Outcomes Scale developed by researchers at Arduin Foundation and Ghent University (POS) and WHO Quality of Life (WHOQoL)) and could be used in other countries, with a view to getting a set of comparable data. The outcomes would offer data for policy planning, costs of the system change – costs for the transition between models and setting up new arrangements and costs for running the system – as well as arguments related to the benefits of supported decision-making. The quality of life evaluation would give the possibility to evaluate long term policy impact and could gather data about the long-term benefits of supported decision-making.

Secondly, comparative analysis of legal frameworks and provisions would provide data to discuss whether such frameworks are in compliance with Article 12. At the moment, only very general presentation of good practice examples can be found in the literature and in policy documents and there is no evidence that existing models qualify as supported decision-making. No legal analysis and comparison of the legal framework is currently available. With time and experience, significant case-law and key aspects of the implementation of Article 12 should be included in comparative analysis. One key issue relates to the disability-neutral criteria to determine access to support. Free access to support legitimately raises the questions of policy planning and public finances. It is necessary to identify the number of people who have the right to access support. The question is how to make sure that those who clearly need support, access it without discrimination and without constraint. So far, no alternative to the recognition of cognitive disabilities has been proposed. One could argue that including cognitive disabilities together with other criteria to access support arrangements could be in line with the principles of Article 12. The question is whether the CRPD Committee would consider this “multiple criteria approach” compatible with the disability-neutral principle.

Legal analysis would also allow setting up of indicators to monitor the implementation of Article 12 in each jurisdiction. Indicators related to legal frameworks and court decisions or to approved agreements should be complemented by further qualitative indicators (availability and accessibility of support, of information about legal capacity, respect of rights and preferences, voluntariness, monitoring of supporters) to offer a comprehensive view on the implementation of Article 12 (CRPD, 2014; ENNHRI, 2020).

This leads to the need for independent and multi-disciplinary evaluation of both the outcomes and implementation of pilot projects and of law and policy reforms. Disability policy research is necessary to evaluate both the legal and administrative framework and the practice and its impact on the life of people with disabilities and to highlight and put problems on the agenda (Tøssebro, 2013).

Finally, at macro level a key question remains unanswered: to whom is the model of supported decision-making relevant? Are people with dementia and age-related illness also in need of supported decision-making? It is an important policy and also political issue which remains almost untouched in this work and in the findings from the pilot projects but will be important in terms of system change. The British Colombian system changed thanks to the support of organisations representing people with dementia and age-related illness[93]; building alliances and expanding networks may reinforce the capacity of civil society to promote legal and policy changes. At the same time, research should help with differentiating practical aspects in terms of determination of support

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[93] Notes from a study visit in Bristish Colombia 2010 – filed with the author.

needs when capacities are reducing, also for ageing people with intellectual and psychosocial disabilities.

To maximise the potential of future pilot projects and take into account lessons learnt, a last section presents key recommendations to design and plan future pilot projects.

9.4 Recommendations for future pilot projects

The pilot projects have faced several challenges over a wide range of issues from the recruitment of pilot participants and the design of tools for their work to political campaigning and involvement in drafting new laws. They have often achieved an enormous amount of work with rather limited resources thanks to the enthusiasm of pioneers and the generally positive impact and feedback they received during the project.

However, this study highlights the lack of a systematic approach in the work of the pilot projects, which diminishes the potential to use and analyse the outcomes in the projects. A more systematic approach would give more evidence for research and practice. A set of twelve recommendations for how future pilot projects should plan and operate their work are set out below. The recommendations presented are once again organised at the micro, mezzo, macro levels.

Research illustrated that so far there was no consistent framework for the evaluation of pilot projects implementing Article 12. The framework developed in Chapter 4 includes nine domains relevant for the implementation of Article 12. It offers a starting point for further developing an implementation tool. Although several questions remained unanswered, the nine domains performed relatively well and key outcomes and gaps have been identified. It could be worth trying and applying in practice the questions of the nine domains as part of a further pilot project. It would of course benefit from adaptations to the local context and environment. Assessing the nine domains would indeed have to go along with the set up new pilot projects.

In addition to the framework domains and its questions, several recommendations regarding the design of pilot projects were identified. These recommendations do not primarily look at the implementation of Article 12, as in the nine domains, but offer learning from experience. Together with the framework, they offer a starting point for more comprehensive implementation of Article 12.

9.4.1 Micro level

1. **Pre-project preparation**: Methods to assess support needs specific to supported decision-making should be developed and tested before the pilot project starts and with different groups – it may be a pre-project in itself. Dedicated time should be given to the development and piloting of these methods, also for people with severe disabilities and complex needs. This would allow the pilot project to start with effective and proven methods. Otherwise, the project runs the risk of having little time for other important activities.
2. **Project participants**: Pilot projects should work with a wider range of people: they should include different groups of people with disabilities (people with intellectual and psychosocial disabilities, autistic people), and take special care in including people with high support needs.
3. **Duration of pilot projects**: Pilot projects should potentially consider working with small groups of people (for example 20 or 25) at one time but over a longer period, for example to plan for a 3-5-year project. A long-term approach would make the participation of people with severe disabilities more likely, as it may take time to learn the person’s specific communication needs and evaluate support needs. It would also enable the support to be organised (by whom for what, how), train and reposition supporters and give time to exercise supported decision-making by practicing decision-making with the newly designated supporter(s). It would also potentially allow the inclusion of a wider range of decisions as they occur naturally over the course of several years.
4. **Regular review about decision-making processes**: Pilot projects should 1) create a simple reporting mechanism of decisions and 2) should include regular meetings involving at least the decision-makers and supporters with a facilitator or a mentor. Regular meetings, should be set to discuss what happened, if decisions were well supported and implemented, what worked and what did not, why a decision could not be implemented, if decisions were revised, where decisions were not taken and why and what can be improved for future decisions. This would provide an opportunity to share experience, reflect about the process and keep the opportunities to grow and develop decision-making skills at the centre of the process.
5. **Focus on day-to-day decision-making**: Pilot projects should aim to deal initially with everyday life decisions and simple legal acts – looking at decisions that are needed. Future planning and long-term goals should come at a later stage, once support arrangements are working.
6. **Capacity building and team work:** Building know-how is an important aspect of the pilot projects: they should maximise the know-how so that more people are trained and ensure that a mechanism to critically reflect

one's work is available (e.g.: work in twin teams to reflect and give feedback, supervision groups for facilitators, mentors). Once the project will enter a scaling-up phase, more people will be able to share and transmit their know-how. Lessons and capacity will not be lost after the pilot project end.

9.4.2 Mezzo level

7. **Communities of practice:** pilot project should establish a network of people that have an interest in supported decision-making to maximise the knowledge and the experience. Meetings of communities of practice would provide space for questions, doubts and to share experiences and knowledge among decision-makers and supporters, but also staff and other interested persons.
8. **Early engagement of health care and banking sectors**: Health care and banking sectors are the most challenging and resistant to change. Pilot projects should get a binding commitment from relevant third parties to participate actively in the pilot – for example, a bank, a hospital, doctors, care providers. It should try to involve those who traditionally encourage the system of substituted decision-making. These could start by making their procedures related to legal capacity accessible, reviewing their communication, information and practices from the perspective of their accessibility duty.
9. **Campaigning to raise awareness**: Developing local campaigns to support a culture change in the society and encourage needed shifts in public perception and attitudes – campaigns could primarily reach the communities of pilot participants. Pilot projects should give more visibility to their work and activities and share their positive experience across different sectors (social service providers, local authorities, health care, finance, justice, schools). Such local campaigns could pave the way for changes in the mind-set of the community and could reach out to actors who could influence future steps.

9.4.3 Macro level

10. **Building evidence:** pilot projects lessons and outcomes are not yet collected as a body of evidence. While there are some examples of pilot evaluations, there is a lack of shared evaluation frameworks and measures. Further studies using common tools and international comparison through research would allow building evidence to address the necessary gaps to implement article 12.
11. **Accessibility of the justice system**: Specific attention should be paid to access to justice, both to ensure procedural accommodations (e.g.: in terms

of communication and accessibility of court procedures and court decisions) and to develop a partnership approach (the justice system is motivated to finding the right support for the person).

12. **Encourage a culture of change**: by building alliances and expanding networks, different groups may promote the right to decide and the change of paradigm necessary to embrace a comprehensive implementation of Article 12. That means changing attitudes and behaviour to move from the culture of protection of people with disabilities to a culture where a person with disability deserves equal recognition.

Last but not least, as mentioned above it seems important to organise piloting at another level, where the implementation of the law, policy, programme and training can be verified. Such system level piloting on site would be necessary to make micro, mezzo and macro levels function together. Comprehensive programmes should be tested at one administrative level (city, region, province) to check the system before it enters into force. In an introducing phase: pilot projects staff and participants could train others and engaged different actors on how to make it work. The responsibility of those programmes should however be managed by a dedicated office in the public administration with the support of organisations of people with disabilities and evaluated by external experts (academics, supporters and decision-makers). Public-private funding may be ideal to pilot on site at the system level.

This dissertation aimed to address the implementation of Article 12 by exploring the outcomes and lessons learnt in six pilot projects. Implementing Article 12 however implies myriad complex issues of law, policy and practice, as this chapter attempts to capture. Pilot projects initiatives are only one element through which this complex process of implementation can be explored.

9.5 Limitations of this research

9.5.1 Limitations of the pilot projects

The analysis of the implementation of Article 12 through pilot projects is a limitation in itself, because of the nature of pilot projects. They were small scale projects, sometimes of a short duration, with a limited number of participants and with limited resources compared to the numerous challenges. The participants were also limited, not only in number but because they included a majority of people with moderate intellectual disabilities, fewer projects also included people with psychosocial disabilities and even fewer projects worked with people with high support needs. Time and staff constraints have also limited the scope of projects.

While longer projects aimed to scale up their activities, the models developed by the pilot projects could not be tested fully. With the participation of the authorities and the collaboration of third parties, many more elements of the system may have been piloted and more feedback could have been discussed.

Another important limitation is that pilot projects have not necessarily produced material for external readers, thus limiting the amount of information and resources available. None of the pilot projects, with the exception of the New York pilot had its own website. Available information was often hidden on an organisation’s website, if publicly available at all. Again, the capacity of the organisations has been mobilised for other essential activities.

9.5.2 Limitations of the comparison and analysis of data

The dissertation had a number of limitations in terms of its research design and data. The analysis to a large extent relied on information given by pilot project staff and project documentation only. The amount of data available was unbalanced between the different projects. In addition, the pilot projects were realised in countries that are culturally and socio-economically diverse and where there differences in disability policy and practice. Comparisons between the pilot projects are limited as the situation of people with disabilities and the social systems are extremely different. This international comparison was a conscious choice for this research, as the notion of supported decision-making has a universal dimension, as does supported decision-making, by its enshrinement in the CRPD.

Data have been accessed in most cases in their original language with the exception of the Bulgarian project[94]. Translations made from original texts were done by the researcher with the objective of respecting the human rights language of the CRPD.

The research therefore relied mainly on secondary data. The data collection methods did not include field work or interviews with pilot project participants themselves. Voices of pilot project participants and case studies had been collected from written reports analysed for the research. Although limited, these have none-the-less been a valuable source of information.

The pilot projects were analysed through a specifically developed framework including nine Article 12 domains which had not been tested or validated before this research. The domains were determined to provide a grid to scan the information and a structure to analyse the pilot projects, but the areas of

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[94] Project material has been published in English by the project.

each domain and the domains themselves have not been validated and they can therefore be discussed and challenged.

This research focused mainly on pilot projects that had potential to allow reflection on the practical implementation of Article 12. Sources other than pilot projects, such as law reforms, would have offered a different perspective, maybe more theoretical.

Finally, the professional involvement of the researcher in the latest phase of the drafting of the CRPD, the implementation of Article 12 and in the realisation of one of the pilot projects on Article 12 has most probably influenced this research. The pilot projects may have been appreciated based on the researcher’s own experience (similar problems or challenges and achievements).

This dissertation was a first attempt to compare and discuss the results of several pilot projects aiming at implementing Article 12 CRPD in different parts of the world. It hopefully contributed to clarifying the challenges in implementing Article 12 in practice and to identifying the necessary elements to design pilot projects in a way that would be more systematic and would provide stronger evidence for policy and legal reforms. The recommendations have not been verified in practice and are simply the conclusions of this dissertation. They may need to be refined and adapted to the local context and the situation of people with disabilities in specific countries. From a policy and legal perspective, pilot projects should be realised at system level to include all three levels – micro, mezzo and macro – to test all the elements of a reform at the same time. Legal reforms would benefit from verified practices. Further research should concentrate on methods for support needs assessment from a decision-making perspective, on longitudinal studies to provide evidence of the benefits of supported decision-making (following the decision-making processes of individuals on a long-term basis), which are linked to progressive empowerment. And last but not least research should focus on the evaluation of supported decision-making programmes, policies and laws.

Legal capacity will have to enter a phase of *transformative equality* to achieve a real change of culture at system level, as pilot project participants experienced. Structural discrimination won't disappear without changes in the cultural and legal environments (Browning et al., 2014). The CRPD recognises *formal equality* – all people with disabilities have equal status, and gives *substantive equality* by redistributing resources and power – guaranteeing the access to support for exercising legal capacity. Building a parallel with the jurisprudence of CEDAW, a third form of equality – *transformative equality* – is needed: *a real transformation of opportunities, institutions and systems so that they are no longer grounded in historically determined (dominant-actor) paradigms of power and life patterns* (Minkowitz, 2017). People with intellectual and psychosocial disabilities, their supporters, their organisations and their allies have to continue mobilising institutions and political leaders to foster the cultural and behavioural changes needed to advance Article 12 implementation.

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Annex

Annex 1: Characteristics of participants in evaluated pilot projects (Chap. 3)

Article 12 Supported Decision Making Pilot, Israel:

22 participants with a wide range of disabilities took part in the pilot project:

- Age: eleven participants were in the 18-30 age range, seven in the 31-59 range and four were over 60 years old.
- Living environment: nine with their families (most of the young people), six independently, four in hostels and three in protected housing.
- Employment: only four in the open labour market, five in protected employment or day care. Nine of them were not working. (Kahana and Yalon-Chamovitz, 2015)

South Australian Supported Decision Making Project:

The project engaged with a wide range of adults, from young people still in schools to older people living in residential care. The age range of participants went from 18 to over 70, with the largest group in the age range 30-49 (8 out of 26) (OPA, 2012). 38% of the participants earned a wage (in addition to their disability pensions). Participants had a variety of accommodation types, ranging from living with their family (36%) to group housing, shared house or private rental (Wallace, 2012). The majority of the participants were not in a relationship (OPA, 2012).

Supported Decision Making Programme, South Australia

A brief project description states "*The decision makers are people with complex needs including physical and intellectual disabilities, with some being non-verbal. Some live in institutional settings and/or are dependent on disability services for most of their needs.*"[95]

Centre for Public Representation and Nonotuck pilot project, Massachusetts

The pilot project included 9 participants (6 women and 3 men) with intellectual and developmental disabilities from 24 to 79 years. All the participants used verbal communication, although 3 had limited abilities. All the participants experienced some medical conditions and behavioural health issues (anxiety,

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[95] See http://www.hcscc.sa.gov.au/wp-content/uploads/2014/10/HCSCC-Overview-of-SDM-Project.pdf (last accessed 27/11/2021)

bi-polar, depression, attention deficit hyperactivity disorder, etc.). The pilot had not considered any participant with more severe or profound disabilities.

All the participants lived either with family (5) or in shared living (4) (which is typically one individual with a disability with a person without a disability who provides some care). Three of them had experienced institutionalisation earlier in their lives.

Annex 2: Framework : nine domains questions and possible indicators

Domains	Questions that are addressed for pilot projects to operationalise Article 12	Possible indicators to look at or measures to test in practice
Domain 1: Being a person before the law	- How did the pilot projects conceptualise equality before the law? - How did the pilot projects understand personhood and which criteria did pilot projects use to define personhood for people with cognitive disabilities?	Criteria defining personhood in practice Techniques to capture life stories of people or their identity Practice guidance to describe will and preferences by others who know the individual well
Domain 2: Determination of support needs	- How did pilot projects determine support needs? What criteria were used to determine support needs and were those disability-neutral criteria? - What tools and methods did pilot projects use to assess support needs? - Who conducted the assessment? How did pilot projects involve the person in the choice of support level he/she requires? - Did the pilot projects combine formal and informal decision-making assistance and if, so, how? How did they assess the need for formal decision-making? - If pilot projects encountered people who refused support, what was their response?	Disability-neutral criteria Support needs assessment methods and tools Facilitator/resource used to assess support needs and areas of formal support Case studies of people who refuse support

Domain 3: **Available supports**	- What support for decision-making was made available/offered by the pilot project? - What concrete tools and measures did pilot projects use? How did pilot projects select them to ensure that the person's will and preferences and human rights were respected? - How projects have conceptualised and used a panel or circle of support to support people in exercising their legal capacity? - What support is offered in relation to decisions concerning financial affairs? housing? health care? voting? entering a contract? Or in relation to personal decisions (work, relationships, leisure time activities and holidays?) - How pilot projects have envisaged freedom of contract for people with cognitive disabilities? What accommodations to the capacity to contract did the pilot projects use?	Description of available supports Tools and measures used Decision-specific tools for certain areas of life Low threshold contract of supported decision-making
Domain 4: **Supporters' role: duties and liabilities**	- What methods or techniques were used to create support networks? How have potential new supporters been reached out to and involved in the life of individuals with disabilities? - What means have been used to explain their duties to supporters? Guidelines/practice guidance? Did pilot projects create different material for family members and friends and other groups of people? - What guidelines have been developed and tested to protect supporters from liability?	Training and educational material for supporters and/or for different groups of support persons involved Practice guidance for creating, enriching support networks Guidelines on supporters' liability

Domain 5: Supported decision-making processes and outcomes	- Which mechanisms did pilot projects create to ensure that decisions are made with respect to the rights, the will and preferences of the person (guidelines, facilitation of decision-processes)? - What monitoring mechanisms have been put in place to evaluate the decision-making process and its outcome? - How have decisions been recorded? What guidelines have been developed to build a history and a track record of supported decisions? - How did pilot projects seek to clarify the difference between best interest decisions and best interpretation of the will and preferences? - If pilot projects are confronted with situations where the will or preferences are unclear or absent, what guidelines have been developed and tested to support the decision-making processes? - Have pilot projects been confronted with emergency situations or situations of serious adverse effect? How did they respond? - How were risks assessed in the pilot project? Has a risk assessment plans been tested in the framework of the pilot projects?	Practice guidance/ethical guidelines to respect the rights and follow the preferences of the person Assessment tool or evaluation method of the decision process and outcome Detailed records of decisions – history of decisions (format, people involved, options discussed) Practice guidance for the best interpretation of the will and preferences Case studies of situations where the will or preferences were unclear Case studies of emergency situations Risk-assessment tools – in the context of decision-making /exercise of legal capacity
Domain 6: Interactions with third parties	- What system has been conceptualised by pilot projects to verify who is a support person? - What experience can be reported from the pilot projects regarding	Documents used to recognise the role of supporters

	interaction with third parties? ○ How did third parties accept or challenge the work done by supporters of pilot participants? ○ Did third parties offer decision-making supports or provide accommodation based on supporters or others' suggestions?	Case-studies of interaction with third parties
Domain 7: Reasonable accommodation	- How have pilot projects worked with the notion of reasonable accommodation in the exercise of legal capacity for individuals or groups of individuals? Have they initiated reasonable accommodation with specific third parties? - Could the pilot projects participants suggest reasonable accommodation? Was it accepted? Was it denied? - Have pilot projects explored possible accommodations or special measures to include vulnerability in contracts?	Case-studies Best practice examples Example of innovative contracts
Domain 8: Safeguards	- How did pilot projects consider and conceptualise informal and formal safeguards? - What did pilot projects plan to advise and support decision-makers, supporters and third parties in case of doubts about their rights and duties? - What role do facilitators play in safeguarding? - What mechanism did pilot projects propose in case of conflict between the decision-maker and the supporter? Who should support a person with disability in a conflict, in order to guarantee his/her fair participation?	Resource person/contact point (as part of the pilot project) Role of the facilitator in safeguarding Conflict resolution mechanism Mediation techniques applied to people with cognitive disabilities

	- How was monitoring conceptualised and planned in the pilot project?
	    o Who should monitor supporters? And what should be monitored (avoiding administrative burden in the life of people with disabilities and their network members)?
	    o How frequent should review of support arrangements take place? Who should facilitate this review?
	    o What out-of-court mechanism(s) can be used?
		Review mechanism (frequency, people involved, methods applied)

Domain 9: The costs of support	- Have pilot projects analysed what resources are needed for formal decision-making with support (the work involved by how many people, how much time and other resources)? - Have pilot projects analysed what resources are needed to achieve decisions made on the best interpretation of the will and preferences of individuals who have no experience or history of decisions? - Have pilot projects analysed what resources are needed to create a support network for people who have no relations and are socially isolated? - What benchmarks have been set to evaluate the quality of life with the supports provided in the exercise of legal capacity to pilot project participants?	Records of the hours of work by type of decisions (including meetings, number of people, side-activities…) Resources needed for important decisions Records of resources invested in creating (or enlarging) support networks Benchmarks, assessment tool of the participants' quality of life with supported decision-making

Annex 3: Preliminary survey for key informants

The objective of the study is to collect information about available data gathered during pilot projects focusing on the implementation of Article 12 CRPD. Data collected will include this survey and an interview with a respondent, as well as available project material (publication, website). Thank you for sharing this information!

About the project:

What is your project name?

What is the duration of your project?

From To

Quantitative data:

- How many people are involved in your pilot project? (people with needs of support in decision-making):
- What are the characteristics of the participants (***please use the space provided with "„ to include any number if you have detailed data available***)
    - type of disability:

      ☐intellectual disabilities:

      ☐psychosocial disabilities:

      ☐dementia:

      ☐others: (please specify)
    - age categories:

      ☐18-25:

      ☐26-39:

      ☐40-59:

      ☐60+:
    - living arrangements:

      ☐residential services:

      ☐supported living:

      ☐independent:

      ☐with family:

- legal status:

  ☐full legal capacity:

  ☐under guardianship or other form of substituted decision-making:

- How many people experience communication difficulties or have no verbal communication?

- How many people with severe disabilities are involved in the project?

- How many supporters are involved (for how many participants):

  ☐1 person

  ☐2-4 persons

  ☐More than 4 people

- What are the characteristics of the supporters
  ☐family members
  ☐friends and acquaintance
  ☐volunteers (not being part of the network of decision-makers)
  ☐professionals
  ☐paid supporters

- Are the areas of support limited to certain areas only, in the design of the pilot project? If yes, what are they?

Project outcomes:

- Did you produce any publication, report or analysis resulting from the pilot work? If yes, can you share them or their online link?

- Is there a project website, video testimonies, articles or any other outreach or propagation material about the project? If yes, can you share them or their online link?

Thank you!

Annex 4: Interviews with key informants

The objective of the interview is to collect information about available data gathered during pilot projects focusing on the implementation of Article 12. Data collected will include a survey, an interview with a key respondent and will be completed by available project material (publication, website)

The interview should have the form of the discussion between the researcher and key informants. The interview guide below is intended to help me to ensure that the same general information is collected from each participant. The prompts have been written in order to think about different situations but they will be used and adapted in a flexible and sensitive manner to respond to the participants' needs and experience.

Additional prompts may be triggered by something that the participant mentioned briefly which would be useful to explore further.

About the project

- What are the concrete objectives of your pilot project?
- Who are the key players involved (formal partners, associated partners, other NGOs, DPOs, state authorities or decision-makers, representatives of the judiciary system, of the social system, representatives of third parties...)?

Qualitative data

Recruitment phase

- How and where did you recruit project participants?
  What are the criteria you set up to allow participation? Why these criteria?
- Did you find it difficult to recruit committed project participants?
  If yes, what are the reasons according to your knowledge?

Implementation phase:

- Did project participants receive any background material, training about supported decision-making? *(both decision-makers and supporters or only one group) If yes, can you please describe it?*
- What sort of material, technics or methods do you use to set up support agreements/settings and the role of supporters/supported persons?
- Do participants sign legally valid support agreements (non-statutory)?
  If yes, how many have been signed? If no, do you use any form of written agreement?
- Do you document the decision-making processes involving supporters?
  (Records of decisions, type of decisions, steps done to reach a decision and implement a decision)? If yes, how do you record it (diary, personal notes, meetings...)?
- What sort of reasonable accommodation in decision-making do you provide to project participants? / do your participants required?

- Do you have a method/a system for the evaluation of the support work done? *(formal or informal)*
- Do you work with third parties *(bank, doctors,...)* on an ad-hoc basis, depending of the needs of each participant? Or do you work at a more systemic level?
  Do you have any example of successful reasonable accommodation by third party?
- Do you organise support for supporters? *(Learning community, supervision, exchange meetings...) If yes, can you describe it? If no, do you use any other from to get a feedback from supporters about their role?*
- *(if applicable)* Did the legal status of some participants change? *(Restoration of legal capacity, new legal instrument in place)*
- According to your experience, what worked well in your pilot? What are the biggest difficulties you encountered? Is there any issue that arose which you did not expect at all?

Outcomes and next steps:

- How do you plan the support of pilot participants after the project?
  Do you have an exit strategy? Are the agreements valid after the end of the project?
- How do you analyse the results of your pilot? What conclusions have you reached?
- How do you transpose the pilot project results in systemic recommendations for changes?
- Are you conducting an external or internal evaluation?
  If yes, what is the evaluation goal? How did you plan feedback from people with intellectual disabilities?
- How did you involve your partners in the analysis of the results and the design of the conclusions? *(Feedback meetings, working groups, discussion over a report, consultations process..)*
- Are you using the results to influence legal reforms and to do advocacy work?
  What are the advocacy objectives you set up based on the pilot project? Can you already report some successes?
- Have you planned other outreach activities?
  If yes, can you please just briefly describe the nature of your outreach activities?

Are you planning a follow-up project? *If yes, what are the objectives of the new project? What will/would you do differently?*

Annex 5: Summary of the pilot projects features (Chap. 6

Country	Date – length of the project	People with support needs involved	Supporters involved	Type of support and/or agreement
Colombia	3.5 years in total: Feb. 2015-Dec. 2016 Mar. 2017-Oct.2018	36 people: • 20 with intellectual disabilities • 16 with psychosocial disabilities	Family members mainly and some supporters from the community	Constitution of a support network (symbolic instrument)
Peru	1.5 year project: 2016-2018	20 people with ID (living in families)	Family members	Non statutory agreement
Zambia	2-year project (2016-2018)	• 30 people with psychosocial disabilities • 30 people with intellectual disabilities	Family members + friends + volunteers from the community	Informal support network
Czech Republic	8 years with interruptions: 2012-2019 (4 phases)	20 + 21 + 13 (54 people in total) + people involved in research (29 + 10) 103 people	Family members, guardians, staff, friends, community volunteers	Legal instruments from the New Civil Code (including SDM)
Bulgaria	6 years Oct. 2012-May 2014 2014-2016 2017-2018	150 people (people with intellectual and psychosocial disabilities)	Family members, friends, community volunteers	Non statutory agreement
New-York	5 years (2016-2021)	79 people with intellectual and developmental disabilities and autism at the end of Year 3	Family members, guardians, staff, friends, community volunteers	Notarised agreement (and health care proxies if the person wishes so)

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Annex 6: Extract of an interview with key informant

Interview with the Director of the Peruvian Society for Down Syndrome (29.6.2018)

(...)
Interviewer (I): I'm also interested about the recruitment of participants in your project. So how and where did you recruit your project participants? How did you do this? How did you choose them?

Respondent (R): We used our newsletter and social networks like Facebook. And we asked the municipalities to reach the families they work with

I: OK. And did you have specific criteria?

R: Yes. One of the things we used to tell families is that if they want to enrol to the project and be part of the workshops and be part of all of this what we are seeking about, they have to be sure that's what they want. That they want the family members to take their own decisions and have their own voice, to be able to have their own dreams and fight for them. So, if they're not willing to do those changes they better don't enter the project. We asked them to have their identity card with them, which is rare that they have it. Normally it's their families who have it because they think they are going to lose it. So to have their identity card and to have a cell phone with them because it is safer and gives more confidence both to the young adults with disabilities and the families. This is a way of being in touch if something goes wrong. They have to sign an agreement or a letter to say we agree to these terms. And some people abandoned the project. Not that many but like out of 20 perhaps to 2 or 3 - I don't have the exact number - because they said that their child was not as obedient as before. They were kind of scared, for example they started to say they want to live on their own or have a partner and they began to say they would get married or look at it and they say well, they were not prepare for it.

I: So but did you have any difficulties in recruiting those 20 people? Or did you have more interested person than the number you needed? If you remember.

R:We did not have much difficulties but it was a tight number. If we would have been willing to have more than 10 because we worked with two municipalities, then it would have been a difficulty. And 10 is a small number.

I: What do you think are the reasons for this tight number of participants? According to your opinion. Why you didn't have like hundreds of people wanting to participate in the project?

R: That would have being great! I think the families are afraid of change. Because when speaking about self- determination and people taking their own positions and giving them freedom, it means that we as families are losing control. I think that's one reason and the other reason is overprotection. Because we think they are like a child even if they are 40 or 50. We think of them as a child. And you don't have in your mind that a child can make decisions on their own. And there is some reluctance to change, you know. It's like we are happy with what we have. How things are settled down, we don't want any changes that can mean trouble. And then another thing that we have been thinking about it is not like a kind of real conclusion. It's more like something that we have highlighted and we would like to work more on it. It's the fact that it is the mothers or the sisters of the person with intellectual disabilities who are the ones who make the decisions. And they are responsible for the good decisions or the bad decisions regarding their family member with a disability. And so they are like pointed it out by the father, even if the father does not live with them, or by the rest of the family: Are you crazy? Are you really gonna let him go to buy on her own? What if he/she gets lost? Or, they can't take public transportation to that address and so if the mothers are willing to make changes, they have a lot of pressure not to make them.

I: OK. That's interesting.

R: That's something we would like to work more on these gender things. Who is the care giver and how is the pressure of their own family and society regarding the changes they're willing to implement. I remember my son, who is twenty nine right now but we started with independency since he was like 8 or 9 years old, like going to buy bread for example, away from home and my neighbour bringing him back and my son was so angry and they were so angry with me because she told me your boy escaped. And I said, no he was just going to buy bread. And she was looking at me, like are you crazy? Are you really letting him go by himself? It is so scary. It's a social pressure and a family pressure. That's very interesting aspect.

I: Yes, thank you. So if I look further, so once you've recruited your participants. How did you start to work? Did participants received material, may be in easy to read or families some trainings about support to decision making, about legal capacity? How did you start? How did you open up the issue with them?

R: Well we developed a tool kit with, I think, twelve sessions, no sixteen sessions for people with disabilities and, I think, it is 10 sessions with the families. And with this tool kit we have workshops: 3hour workshop weekly for the young adults and for the families it was one session per month.

I: During the whole duration of the project?

R: No, just for this number of sessions. The project was 18 months. The workshops were four months. And then we had time in between as the two groups did not start together. We started with one and then with the other one. And then we had like, I think, three months' time to see what they have been able to do. Because one of the activities that we developed is PATH, if you know PATH it's from person centered planning?

I: Yes, very well. We work with PATH as well.

R: So, they had to identify their dreams. They had to identify the ways to reach those dreams. And. Well you know PATH it's like : Plans for Alternatives for Tomorrows with Hope. That’s the one. So you identify a dream. And then you go back to see what is needed to be done, so you can achieve that. Yes. So this planning tool. We developed this pack with the adult with a person with a disability and the people that he or she wants to be part into this PATH process. And then we gave like 3 months before a first interview to see what they have achieved. And then we gave another 3 month to see what finally happened.
One of the things that we have done out of our organisation – we required from the University an external evaluation of the whole process. And then one of the things that we have seen is that we need to be nearer to the families and to the person if we really want changes to happen. Sometimes it is difficult to make changes when you have been working in a certain way for years. And it is not easy to change and it is more difficult, if you feel that you are alone. So that's something that we have to do thing about it and make some changes. But the biggest issue is the difficulty of having municipalities engaged with this new idea related to persons with disabilities. So, finding facilitators and trained them and having the municipalities engaged with and committed to the goal of our project, has been a challenge.
So the facilitators... We would like the municipalities to use the tool-kit by their own. And of course pay the people with the facilitator and the people they need to work. And that's another challenge.

I: So just to make sure I understand correctly the facilitators were the people who helped with PATH. Who helped them to identify the dreams, the steps, the who does what and all this. That was the role of the facilitators?

R: Yes, they were paid by the Peruvian Down Syndrome Society as part of the project. But we were willing for the municipalities to commit with this project and by developing the project in the coming years by their own. And that's a challenge.

(…)

Annex 7: Nine Inspiring Practices from the Pilot Projects

Inspiring practice 1: Procedure to assess trust relationship

The Bulgarian model has tried to define criteria to measure a good supporting relationship while leaving it open to the complexity and individuality of each relationship. For this purpose, procedural rules for the evaluation of trusted relationships include hearing of the decision-maker and supporter(s) in appropriate and friendly conditions by the judge or his/her judicial assistant: it must be confidential, organised in a safe environment and include people close to the person needing support. ONLY if this would prove to be insufficient then an expert's opinion can be sought. The importance of respecting the feelings and perceptions of people with disabilities, even if they are not formulated "correctly" in terms of normal communication has been highlighted in the legislation and in the guidance material (BG_DOC_2).

Inspiring practice 2: Mapping family and social support networks

The **ECOMAPA** created by the Colombia project provides a simple tool for mapping community opportunities by assessing the person’s support needs and the availability of such support and how it can be provided. It complements the map of relationships used to identify closest supporters and allows mapping the person's relationships with the family, his/her social network and the community. It facilitates the identification of community support, determining where relationships are strongest and where weakest, and which could be strengthened as support networks for decision making. It points out who and where a greater role can be played in supported decision-making (CO_DOC_7). See figure 3 below. In the centre of the diagram is the person with a disability and around the entities playing a role in the life of the person identified with names and images: health, education, work, recreation, culture, religion, organisations of persons with disabilities and extended family. Connections between them are made through lines that connect the central person with the circles around them, depending on their intensity and type of bond between them.

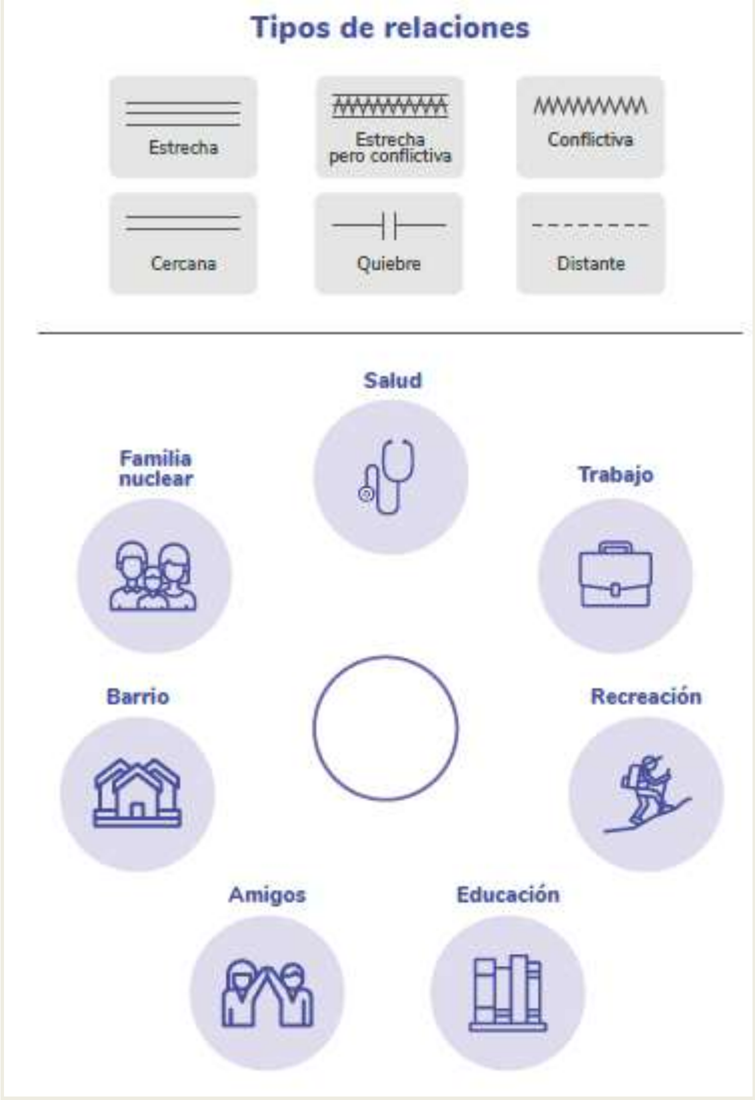
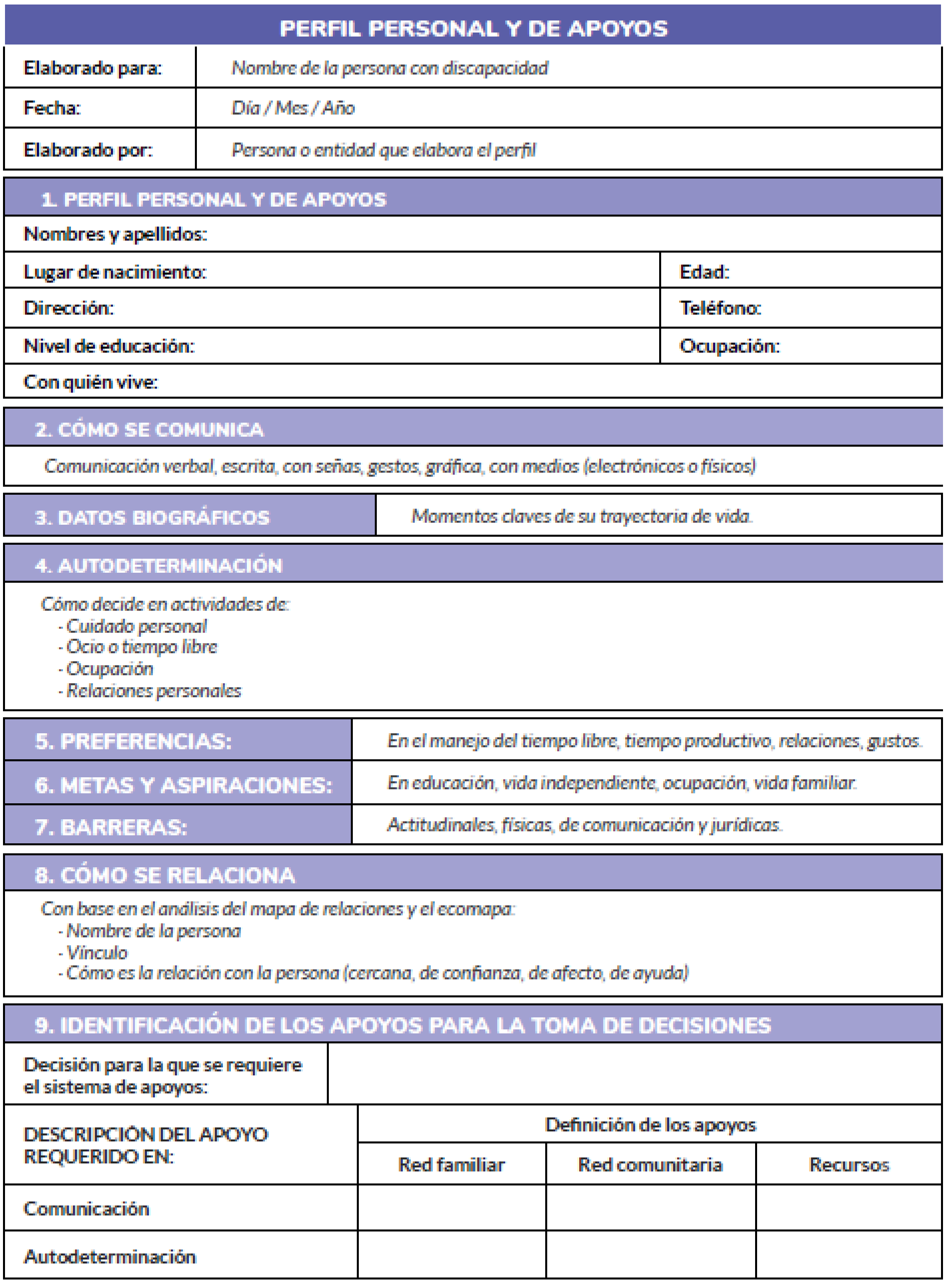


Figure 3: Tool for mapping community resources and opportunities and types of relationships (Ecomapa)

Inspiring practice 3: Personal and supports profile

The Colombian project created a booklet named "**Personal and supports profile**" which was given to project participants. This document summarises personal information and strategies that are considered to provide support in decision making to people with disabilities. In general, the document contains: report of the person's life project according to his/her preferences, the adjustments and supports that the person requires to participate in a decision-making process and who are the supporters to help with certain decisions. It also includes information about communication needs, abilities and barriers the person may be facing. The support needs include all types of support as required by the person. This document is the result of the project work and was given to each person participating. Such a profile may be important for the person, to be able to come back to it, but also for his/her supporters and potentially it might be a useful social work tool for new and additional staff involved. Last but not least, it can be easily updated. The tool is only provided as a template to be filled with words – this format may not be accessible to all. However, the idea to create such a booklet, in different alternative formats, is an important step – the idea is that it should be something simple, small and practical to stay with the person and be understandable to others. See the template of the personal profile and supports below



PERFIL PERSONAL Y DE APOYOS

Elaborado para:	*Nombre de la persona con discapacidad*
Fecha:	*Día / Mes / Año*
Elaborado por:	*Persona o entidad que elabora el perfil*

1. PERFIL PERSONAL Y DE APOYOS	
Nombres y apellidos:	
Lugar de nacimiento:	**Edad:**
Dirección:	**Teléfono:**
Nivel de educación:	**Ocupación:**
Con quién vive:	

2. CÓMO SE COMUNICA

Comunicación verbal, escrita, con señas, gestos, gráfica, con medios (electrónicos o físicos)

3. DATOS BIOGRÁFICOS	*Momentos claves de su trayectoria de vida.*

4. AUTODETERMINACIÓN

Cómo decide en actividades de:
- *Cuidado personal*
- *Ocio o tiempo libre*
- *Ocupación*
- *Relaciones personales*

5. PREFERENCIAS:	*En el manejo del tiempo libre, tiempo productivo, relaciones, gustos.*
6. METAS Y ASPIRACIONES:	*En educación, vida independiente, ocupación, vida familiar.*
7. BARRERAS:	*Actitudinales, físicas, de comunicación y jurídicas.*

8. CÓMO SE RELACIONA

Con base en el análisis del mapa de relaciones y el ecomapa:
- *Nombre de la persona*
- *Vínculo*
- *Cómo es la relación con la persona (cercana, de confianza, de afecto, de ayuda)*

9. IDENTIFICACIÓN DE LOS APOYOS PARA LA TOMA DE DECISIONES

Decisión para la que se requiere el sistema de apoyos:	

DESCRIPCIÓN DEL APOYO REQUERIDO EN:	**Definición de los apoyos**		
	Red familiar	**Red comunitaria**	**Recursos**
Comunicación			
Autodeterminación			

Inspiring practice 4: Repositioning supporters

Empowerment of supporters and relatives is as important as capacity building of people with disabilities themselves. The notion of "re-positioning" supporters is an interesting notion developed by the New York pilot project to describe the new dynamics. It describes a process that *"offer(s) a different, more hopeful vision of the person with I/DD as someone who could, and should, learn and grow, be afforded, and earn respect. It includes thoughtful consideration of "the dignity of risk" that encourages parents to see that an excessive emphasis on protection not only infantilises their adult children, but also deprives them of the ability to experience responsibility for their actions, and to learn from their mistakes*" (NY_DOC_3).

In the New York pilot, the facilitator works with the supporters the decision-maker has chosen, educating them about SDM, and helping them "reposition" from people who make decisions for the decision-maker to supporting her or him in making her or his own decision (NY_DOC_1).

Opposing the RESCUER versus the SUPPORTER gives an interesting picture of what "reposition" means in practice and gives a good basis for discussion and reflection about the new role of supporters:

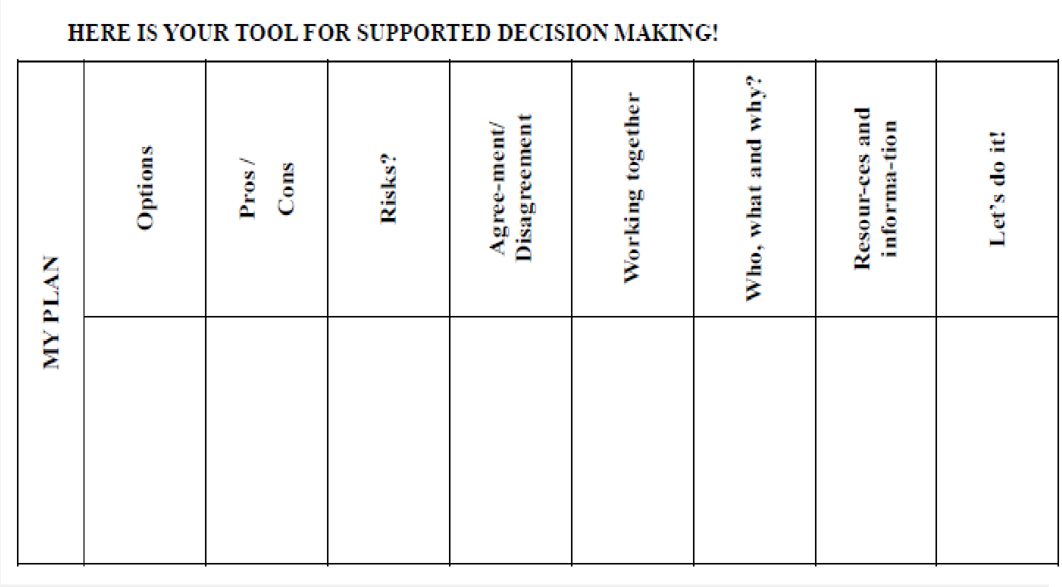
RESCUER	SUPPORTER
gives advice, controls, knows best, disempowers, jumps to conclusions, doesn't listen, talks a lot	listens, respects, reflects, explores, assists, empowers

(NY_DOC_5 – inspired from the training by Cher Nicholson)

Inspiring practice 5: A tool for supported decision-making

In terms of learning how to make supported decisions, an interesting and simple **tool for supported decision-making** was designed by the Bulgarian project. It is a template form to record how a supported decision was made – it should apply for any kind of decision. While it is not known to the researcher how frequently it has been tested in practice, it is part of practice guidance developed, tested and used by the project Step by Step (BG_DOC_1).

The tool allows recording the important steps for a simple or a more complex decision, and it can be done with one or more supporters. Some answers could be drawn and/or written in words, depending on the reading skills of each person and the tool seems to work for all persons with disabilities. By writing down the different steps (the options envisaged, the risks, the information given to the person and by whom), the table guides all the participants on a supported decision-making path. It also allows coming back to the history of the decisions and the other options in case the decision was not the right one. The tool could be quickly and easily translated into other languages so that it could be used by others. How to use the table is described in the frame below.



HERE IS YOUR TOOL FOR SUPPORTED DECISION MAKING!

MY PLAN	Options	Pros / Cons	Risks?	Agree-ment/ Disagreement	Working together	Who, what and why?	Resour-ces and informa-tion	Let's do it!

Figure 4: Supported decision-making reporting tool

Put down the decisions you will discuss together in the provided space.
OPTIONS:
Write down all possible methods which you can achieve together through brainstorming. What are some actions you can try in order to assist the achievement of the results?
During the brainstorming, everyone should keep in mind what is important for the person, what kind of person they are, how they communicate.
The more options you identify, the bigger the odds for success!
Mark each option with “1, 2, 3” or “a, b, c” for future use.
Collect information and seek advice inside and outside the group (when necessary).
PROS/CONS
Write down the pros and cons for each option (1, 2, 3 or a, b, c).
This will take time –brainstorming and then sharing your ideas based on your relationships and connections.
RISKS
Everyone uses this opportunity to express their fears or hesitations in relation to each option by weighing the pros and cons and assessing the level of risk (see the reflection circle). This is done to make sure everyone can express their concerns and share the responsibility for the risk as a member of the team.
Determine if this is a manageable risk or if there is a risk at all, consider every option. Write down all risks and all your thoughts.
DISAGREEMENT/AGREEMENT?
Having heard everything, now is the time to choose the most convenient option. Go through what you have written so far.
Determine how you are going to do that.
- Consensus
- Present the options to the planning person and have them choose which one they will try

- Other
- What happens if there is disagreement? Now that you have all the information is the time to work on disagreement.
- Now is the time to get to an action that will help everyone work on results.
- Write down how you are going to make a decision and what decision was made to show that everyone made a commitment.

WORKING TOGETHER

What does it take? How are we going to work together? Highlight the steps you will need to fill to achieve a result/decision.

WHO, WHAT AND WHY?

For each step, determine who will do what. Mention why this person was nominated (so that the same person does not do everything) to support the person in achieving a result.

Talk about why each person was nominated for a certain part of the result/decision. Write it down.

Mark a completion schedule.

Nominate a person to collect/share information upon receipt. Talk about and write down how the information will be shared.

RESOURCES AND INFORMATION

Will you need additional information and resources? Put this down here. How will they be accessible?

Indicate who will collect the information starting when.

LET'S DO IT!

Once all parts are in place, set them going. The choice has been made...now we are working on the decision. Encouraging words are an idea!

LET'S THINK TOGETHER!

How do things work out? Evaluate the results –see if things work out.

(Reasons to celebrate, challenges, successes, dilemmas, positive things are included here.)

Let's think together!

What else can we try? **Or**let's celebrate together?

Look at what happened. Is this what you want? If no, why not?

What have you tried?

What have you learned?

What are you happy about?

What are you concerned about?

CONSIDERATIONS and OVERVIEW

Write these here–address your other options when you seek to try something else. Start using the tool again for the next option –start by filling in the Working Together section and move forward.

Or write down how you will celebrate your success together if things happen as planned. Celebrating your success does not only give an impetus, it also strengthens the team

Inspiring practice 6: Provision about honouring decisions of the decision-maker

The following provision was included in the New York template: it contained a statement that the decision-maker wishes third parties to honour her/his decisions, provides that the decision-maker is not obligated to use support in making her/his decisions. The project leader described that this was an important provision for self-advocates who feared that signing an agreement of supported decision-making might be used to show they were "incompetent," and that services might be refused if they chose not to use support in a particular situation (NY_DOC_3).

Inspiring practice 7: Reasonable accommodation in banking services

A good practice example at a retail bank was developed in the Czech Republic, where a supporter and a supported person managed to set tailor-made rules. Basically, they adapted the minimum amounts of cash that he could handle, so that he could pick up small amounts more often, so it would work for him. Similarly, he could only withdraw small amounts with his card (setting up limits). To withdraw larger amounts, or reset current limits, he would have to be with his supporter. However, he managed to find a moment when there was a different clerk at the bank, not the one who had arranged these rules with them, and he took a friend with him who he introduced as a supporter and they withdrew what they wanted. So, in practice, it didn't work well. It would probably have required the staff to be trained, to be prepared to deal with these situations. But the bank was willing to adapt the rules for this client both online and at the counter, and was willing to accommodate his needs in terms of money management (CZ_INT_1).

Discussions with the Czech Banks Association have been on-going, to facilitate the introduction of similar arrangements for people with disabilities (CZ_INT_1). For example, a template for a special three-party contract (bank, supporter, supported person), designed pro bono by a law firm has been sent to the Czech Banks Association (CZ_DOC_10) but no response has been given yet. Nevertheless, these discussions and trials are very important to raise awareness and prepare future steps in the field (CZ_INT_1).

Inspiring practice 8: Procedural accommodation to maximise the accessibility and the participation of people with disabilities in legal capacity proceedings

The Colombian legislation includes two procedural accommodations in legal capacity proceedings

- the judgment on supported decision-making will be produced in easy-to-read form for the person concerned

- a guarantee for reasonable accommodation in the judicial proceedings about supports – for communication in the process or any other accommodation needed to satisfy the needs of the persons with disabilities.

These provisions maximise the accessibility of the legal system to the person.

Inspiring practice 9: Instruments for a cost benefit analysis

The cost benefit analysis conducted in the Bulgarian pilot project used two different instruments for measuring quality of life, for the non-monetised benefits, namely the personal outcome scale (POS) for the people with intellectual disabilities and the WHO Quality of Life (WHOQoL) questionnaire for persons with psychosocial disabilities (BG_DOC_3). The POS is based on a conceptual framework, which assumes the multidimensional character of the quality of life concept. The domains are, according to the Conceptual Framework of Quality of Life (Schalock, Bonham, & Verdugo, 2008), as follows: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical wellbeing, material well-being. The questionnaire of the WHO Quality of Life takes the approach that quality of life is a subjective evaluation, which is determined by the context, the culture and the values of the individual. The WHO questionnaire aims to assess the quality of life such as the individual believes that it is. That is why the questionnaire is for self-assessment.

For the analysis of the monetised benefits, desk research on the costs of the different services as well as data collected from a special instrument for pilot project participants, an open questionnaire for assessment of the level of independency, the needs and the perspective of the clients have been used. The analysis of the questionnaires was conducted aiming at determining the “right amount of support” for the clients and also to obtain information about their perspective. For the group of clients from the pilot project the questionnaire has been filled in twice in a period of six months measuring the improvement/change of conditions before and after supported decision-making (BG_DOC_3).