

The CRPD and a paradigm shift to legal capacity: A human rights based examination of the right to equal recognition before the law of persons with intellectual disabilities in Finland

(Vammaissopimus ja oikeustoimikelpoisuuden paradigmanmuutos. Kehitysvammaisten henkilöiden oikeus yhdenvertaisuuteen lain edessä – ihmisoikeusperustainen tarkastelu Suomen kontekstissa)

Nelly Vikkula



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ALUKSI

Tässä julkaistava teksti on Nelly Vikkulan oikeustieteen maisterin tutkinnon pro gradu-tutkielma (valtiosääntöoikeus). Tiivistelmä on toimitettu suomeksi tätä julkaisua varten. Kiitos Nelly Vikkulalle mahdollisuudesta julkaista tämä tutkielma osana Lakitoimisto Kumpuvuori Oy Vammaisoikeuden Julkaisusarja B:tä. Julkaisusta on varmasti iloa ja hyötyä monelle vammaisoikeustoimijalle. Julkaisussa tarkastellaan poikkeuksellisen analyyttisesti vammaisoikeuksia ja annetaan samalla hyviä työkaluja lainsäätäjälle kehittää lainsäädäntöä entistäkin enemmän vammaisten henkilöiden ihmisoikeuksia kunnioittavaan ja turvaavaan suuntaan. Englanninkielisenä Vikkulan teksti antaa myös lisäpontta kansainväliselle tieteelliselle ja vammaispoliittiselle keskustelulle. Julkistaminen tapahtuu Lakitoimisto Kumpuvuori Oy:n järjestämässä ”Vammaissopimus Suomen oikeudessa” – miniseminaarissa Kiasmassa.

Helsinki, 31.8.2016
Jukka Kumpuvuori

TIIVISTELMÄ SUOMEKSI

Vammaissopimus ja oikeustoimikelpoisuuden paradigmanmuutos

Kehitysvammaisten henkilöiden oikeus yhdenvertaisuuteen lain edessä - ihmisoikeusperustainen tarkastelu Suomen kontekstissa

Edunvalvonnan eri muodot ovat olleet erilaisten oikeudellisten uudistusten kohteena ympäri maailmaan, mutta nyt käynnissä oleva uudistus haastaa koko edunvalvonnan olemassaolon. Yhdistyneiden kansakuntien yleissopimuksen vammaisten henkilöiden oikeuksista 12 artiklan on katsottu olevan oikeustoimikelpoisuuden paradigmanmuutoksen ruumiillistuma. Tässä opinnäytetyössä tarkastellaan sitä, mikä on vammaissopimuksen 12 artiklan oikeuden yhdenvertaisuuteen lain edessä normatiivinen sisältö, sekä sen valtiolle asettamia velvollisuuksia. Lisäksi, opinnäytetyössä tarkastellaan relevanttia suomalaista lainsäädäntöä tarkoituksena arvioida, mitä muutoksia mahdollisesti olisi tarpeen tehdä sen jälkeen, kun Suomi on ratifioinut vammaissopimuksen.

Artikla 12:ta on pidetty yhtenä kiistellyimmistä vammaissopimuksen artikloista ja, sen vuoksi, se on johtanut useisiin tulkintoihin. Keskustelu koskee sitä, edellyttääkö 12 artikla jäsenvaltioita poistamaan kaikki päätöksenteon järjestelmät, joissa toinen henkilö päättää kehitysvammaisen henkilön puolesta vai voitaisiinko tällaisia järjestelmiä edelleen pitää sallittuna, mikäli niitä käytetään vain viimeisenä keinona. 12 artikla takaa vammaisille henkilöille oikeuden saada tukea heidän oikeustoimikelpoisuutensa käyttämiseen. Oikeudella tällaiseen tukeen on potentiaalia vaikuttaa henkilönä olemisen moraalifilosofisiin perusteisiin ja ymmärrykseemme itsemääräämisoikeudesta. Vammaissopimus perustuu sellaiseen käsitykseen henkilönä olemista, joka ei anna etusijaa rationaalisuudelle ja tunnistaa ihmisten väliset riippuvuussuhteet.

Vammaissopimuksen neuvotteluprosessin aikana esiteltiin tuetun päätöksenteon idea oikeudellisena viitekehyksenä, joka tarjoaisi mahdollisuuden täyttää velvollisuus tarjota tukea oikeustoimikelpoisuuden harjoittamisessa. Tuettu päätöksenteko voi ilmetä eri muodoissa, mikä mahdollistaa jäsenvaltioiden erilaisten kulttuuristen ja poliittisten elementtien huomioimisen. Tuettu päätöksenteko kunnioittaa henkilön tahtoa ja

mieltymyksiä, samalla turvaten vapautta hyväksikäytöstä. Keskeinen ero kehitysvammaisen henkilön puolesta päättämisen ja tuetun päätöksenteon välillä on, että tuettu päätöksenteko edellyttää objektiivisen ”henkilön edun”-periaatteen (best interests) korvaamista sillä, että kunnioitetaan henkilön omaa tahtoa ja mieltymyksiä.

Laki holhoustoimesta ei perustu sellaiselle käsitykselle itsemääräämisoikeudesta, jota vammaisoikeussopimus edellyttää. Laki holhoustoimesta perustuu ”henkilön edun”-periaatteelle, eikä holhouksenalaisen mielipide ole sitova suhteessa edunvalvojaan. Edelleen, laki holhoustoimesta mahdollistaa vajaavaltaiseksi julistamisen, samoin kuin holhouksenalaisen henkilön oikeuksien rajoittamisen. Tällaisen oikeuksien rajoittamisen voidaan argumentoida olevan vaikutuksiltaan syrjivä. Lailla holhoustoimesta on potentiaalia täyttää tuetun päätöksenteon edellytykset, jos tarvittavat muutokset lakiin tehdään. Vammaisten henkilöiden erityispalveluja koskeva laki, jota parhaillaan luonnostellaan, sisältäisi säännökset oikeudesta tuettuun päätöksentekoon. Vaikuttaa lupaavalta, että Suomella olisi lakisääteinen tuetun päätöksenteon järjestelmä lähitulevaisuudessa.

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law of persons with intellectual disabilities in Finland

Nelly Vikkula

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Faculty of Law

Tiedekunta/Osasto Fakultet/Sektion – Faculty	Laitos/Institution– Department
Faculty of Law	
Tekijä/Författare – Author	
Nelly Vikkula	

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Tiivistelmä/Referat – Abstract <p>Regimes of guardianship have been subject to various legal reforms around the world, but the current wave challenges their very existence. Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) has been considered as the embodiment of a paradigm shift in legal capacity. This thesis examines the normative content of the right to equal recognition before the law of Article 12 of the CRPD and the obligations it sets out to States parties. In addition, this thesis reviews the relevant Finnish legislation in order to assess what changes might be required to be made after Finland has ratified the Convention.</p> <p>Article 12 has been one of the most contentious Articles in the Convention and, consequently, it has generated several interpretations. The debate concerns the issue of whether Article 12 of the CRPD obligates States parties to abolish all regimes of substituted decision-making or if substituted decision-making could still be allowed as a last resort. Article 12 provides persons with disabilities with a right to receive support in the exercise of legal capacity. The right to support has potential to influence the foundational premises of personhood in moral philosophy and our understanding of autonomy. The CRPD is based on a perception of personhood which does not give primacy to rationality and recognizes the interdependence of all individuals.</p> <p>During the negotiations of the CRPD a system of supported decision-making was presented as the legal framework that could fulfil the obligation to provide support in the exercise of legal capacity. A system of supported decision-making can take various different forms, which allows States parties to take into account their specific cultural and political framework. Supported decision-making respects person's will and preferences while also protecting the right to be free from abuse and exploitation. The prominent difference between substituted decision-making and supported decision-making is that supported decision-making demands replacing the principle of objective "best interests" of a person with the principle of respecting the person's will and preferences.</p> <p>The Guardianship Services Act (GSA) in Finland is not regulated upon the kind of construction of a person's right to self-determination required by the CRPD. The GSA is precisely based on the principle of "best interests" and the opinion of a principal is not binding on the guardian. Furthermore, the GSA allows the declaration of incapacity as well as restrictions on a principal's right to exercise rights, which can be argued to be discriminatory in effect. The support guardian in the GSA has potential to fulfil the requirements for supported decision-making, if the necessary changes to the Act will be made. The Act concerning special services of persons with disabilities, which is currently being drafted, would contain a provision on the right to receive support in decision-making. It appears promising that Finland will have a statutory provision on supported decision-making in the near future.</p>		
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Bibliography

Literature

Aarnio, Aulis, 1978, *Mitä lainoppi on?*, Helsinki: Tammi.

Arnardóttir, O.M. and Quinn, G. (Eds.), 2009, Introduction, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff,

Arstein-Kerslake, Anna, 2015, A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, Vol.5.

Bossuyt, Marc J., 1987, Guide to the “Travaux Préparatoires” of the International Covenant on Civil and Political Rights, Martinus Nijhoff.

Dimopoulos, Andreas, 2010, *Issues in Human Rights Protection of Intellectually Disabled Persons*, Burlington, VT: Ashgate.

Flóvenz, Brynhildur G., 2009, The Implementation of the UN Convention and the Development of Economical and Social Rights as Human Rights, in Arnardóttir, O.M. & Quinn, G. (Eds.), 2009, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff.

Garner, Bryan A. (Ed.), 1999, *Black’s Law Dictionary*, 7th Edition, West Group.

Gustavsson, A., Tøssebro, J., & Traustadóttir, R., (2005), Introduction: Approaches and perspectives in the Nordic disability research, in a Gustavsson, A., Sandvin, J., Traustadóttir, R., & Tøssebro, J. (Eds.), *Resistance, reflection, and change: Nordic disability research*, Lund: Studentlitteratur.

Hanski, R. & Scheinin, M., 2007, *Leading Cases of the Human Rights Committee*, 2nd revised edition, Turku: Institute for Human Rights, Åbo Akademi University.

Häyhä, Juha, 1996, Oikeuskelpoisuus, in *Encyclopædia iuridica Fennica*, 3rd edition, Suomalaisen lakimiesyhdistyksen julkaisuja, C-sarja, nro.26, Suomalainen lakimiesyhdistys, Helsinki.

Joseph, S., Schultz, J., Castan, M., 2004, *The International Covenant on Civil and Political Rights: Cases, Materials and Commentary*, 2nd edition, Oxford University Press.

Keller, H., Ulfstein, G., Grover, L., 2012, *UN Human Rights Treaty Bodies. Law and Legitimacy*, Cambridge: Cambridge University Press.

Kittay, Eva Feder, 1999, *Love’s labor: Essays on women, equality, and dependency*, New York: Routledge.

Kumpuvuori, J., & Scheinin, M., 2009, Treating the Different Ones Differently – a Vehicle for Equality for Persons with Disabilities? Implications of Article 5 of the Convention on the Rights of Persons with Disabilities, in Kumpuvuori, J., & Scheinin, M. (Eds.), *United Nations Convention on the Rights of Persons with Disabilities – Multidisciplinary Perspectives*, Helsinki: The Center for Human Rights of Persons with Disabilities in Finland (VIKE).

- Lehrer, Jonah, 2009, *How We Decide*. New York: Houghton Mifflin Harcourt Publishing Company.
- Mallet, R. & Runswick-Cole, K., 2014, *Approaching Disability*, NY: Routledge, Taylor and Francis eBooks, Web.
- Nussbaum, Martha, 2006, *Frontiers of Justice: Disability, Nationality, Species Membership*, Cambridge, MA: Harvard University Press.
- O’Cinneide, Colm, 2009, Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities, in Arnardóttir, O.M. & Quinn, G. (Eds.), *the UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff.
- Petman, Jarna, 2009, The Special Reaching for the Universal: Why a Special Convention for Persons with Disabilities?, in Kumpuvuori, J., & Scheinin, M. (Eds.), *United Nations Convention on the Rights of Persons with Disabilities – Multidisciplinary Perspectives*, Helsinki: The Center for Human Rights of Persons with Disabilities in Finland (VIKE).
- Quinn, G. & Arstein-Kerslake, A., 2012, Restoring the “human” in “human rights”, in Gearty, C. & Douzinas, C. (Eds.), *Cambridge Companion to Human Rights Law*, Cambridge: Cambridge University Press.
- Rawls, John, 1999, *A Theory of Justice* (rev. edn), Oxford: Oxford University Press.
- Rawls, John, 2005, *Political Liberalism*, Expanded Edition, New York: Columbia University Press.
- Saarenpää, Ahti, 2005, Edunvalvonta, jäämistö ja jäämistösuunnittelun mahdollisuudet, in Tepora J., Tulokas M., Vihervuori P., *Juhlaulkaisu Juhani Wirilander 1935-30/11-2005*, Helsinki : Suomalainen Lakimiesyhdistys.
- Saarenpää, Ahti, 2012, Henkilö ja persoonallisuusosoikeus, in Tammilehto, Timo, *Oikeusjärjestys, Osa I*, 8 edition, Lapin yliopiston oikeustieteellisiä julkaisuja, Series C 59.
- Saarenpää, Ahti, 2015, Henkilö- ja persoonallisuusosoikeus, in Niemi, Marja-Leena (Ed.), *Oikeus tänään*, Lapin yliopiston oikeustieteellisiä julkaisuja. Sarja C, Rovaniemi, Lapin yliopisto.
- Saarenpää, Ahti, 2000, Holhouksesta edunvalvontaan, Pohjois-Suomen tuomarikoulu, Julkaisuja 1–2/2000, Rovaniemi.
- Shakespeare, Tom, *The Social Model of Disability*, Davis, Lennard J. (Ed.) in *Disability Studies Reader*, New York: Routledge.
- Smith, Steven R., 2009, Social Justice and Disability; Competing interpretations of the medical and social models, in Kristjana Kristiansen, Simo Vehmas, & Tom Shakespeare, (Eds.), *Arguing about Disability: Philosophical Perspectives*, New York: Routledge.
- Stein, M.A. & Lord, J.E., 2009, Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities, , in Arnardóttir, O.M. & Quinn, G. (Eds.), 2009, *the UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff.
- Timonen, Pekka, 1998, Johdatus lainopin metodiin ja lainopilliseen kirjoittamiseen, Helsinki: Helsingin yliopiston oikeustieteellinen tiedekunta.

Tomuschat, Christian, 2008, *Human Rights: Between Idealism and Realism*, 2nd edition, Oxford University Press.

Tornberg, Johanna, Edunvalvontaoikeus, in Kuuliala, Matti & Tornberg, Johanna (Eds.), *Suomen edunvalvontaoikeus*, Helsinki: Talentum.

Tornberg, Johanna, 2012, *Edunvalvonta, itsemääräämisoikeus ja oikeudellinen laatu*, Rovaniemi: Lapin yliopistopaino, doctoral dissertation.

Traustadóttir, Rannveig, Disability Studies, the Social Model and Legal Developments, in Arnardóttir, O.M. & Quinn, G. (Eds.), 2009, *the UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff.

Vehmas, Simo, 2005, *Vammaisuus; Johdatus historian, teoriaan ja etiikkaan*, Helsinki: Gaudeamus.

Vivanti, Donata, 2015, *Persons with Disabilities and the Right to Equality Before the Law: Contribution from the European Disability Forum*, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*.

Välimäki, Pertti, 2014, *Edunvalvontaoikeus*, Helsinki: Talentum.

Välimäki, Pertti, 2008, *Holhoustoimen pääpiirteet*, Helsinki: WSOY Pro.

Wong, Sophia L., 2010, *Duties of Justice to Citizens with Cognitive Disabilities*, in Kittay, E. F. and Carlson L. (Eds.), *Cognitive Disability and its Challenge to Moral Philosophy*, Chichester: Wiley- Blackwell Publishers.

Articles

Adrian Ward, 2011, *Adults with Incapacity: Freedom and Liberty, Rights and Status: Part 1*, 5 *Scots Law Times* 21.

Arstein-Kerslake, Anna & Flynn, Eilíonóir, (2015), *The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law*, 20(4) *The International Journal of Human Rights*.

Arstein-Kerslake, Anna & Flynn, Eilíonóir, 2014, *The Support Model of Legal Capacity: Fact, Fiction or Fantasy?*, 32(1) *Berkeley Journal of International Law*.

Booth Glen, Kristin, 2012, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond*, *Columbia Human Rights Law Review*, 44.

Browning, M., Bigby, C., & Douglas, J., 2014, *Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice*, *Research & Practice in Intellectual & Developmental Disabilities*, 1(1).

Carbert, Anne & Rioux, Marcia, 2003, *Human Rights and Disability: The International Context*, *Journal on Developmental Disabilities* 10(2).

Carney, Terry & Beaupert, Fleur, 2013, *Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making*, 36 *University of New South Wales Law Journal* 175.

Carney, Terry, 2014, Clarifying, Operationalising, and Evaluating Supported Decision Making Models, *Research and Practice in Intellectual and Developmental Disabilities*, 1(1).

Davy, Laura, 2015, Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory, *Hypatia* 30(1).

Dhanda, Amita, 2006–2007, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?, *Syracuse Journal of International Law and Commerce* 34.

Dinerstein, Robert, 2012, Implementing legal capacity under article 12 of the UN convention on the rights of persons with disabilities: the difficult road from guardianship to supported decision-making, *Human Rights Brief*, 19(2).

Flynn, E. & Arstein-Kerslake, A., 2014, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity', *International Journal of Law in Context*, 10(1).

Gooding, Piers, 2015, Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review* (accepted for publication).

Gooding, Piers, 2012, Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law, *Psychiatry, Psychology and Law* 1.

Gordon, Robert, M., 2000, The Emergence of Assisted (Supported) Decision- Making in the Canadian Law of Adult Guardianship and Substitute Decision- Making, 23 *Int'l J.L. & Psychiatry* 61.

Helin, Markku, 2001, Edunvalvojan päätösvallan rajoista, *Lakimies* 6–7/2001, 1070–1088.

Kanter, Arlene S., 2007, The promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities, 34(2) *Syracuse Journal of International Law and Commerce*.

Kayess, R. & French, P., Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities, *Human Rights Law Review*. 8:1, Oxford University Press. 2008.

Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4.

Lewis, Oliver, 2011, Advancing Legal Capacity Jurisprudence, 6 *European Human Rights Law Review* 700.

McSherry, Bernadette, 2012, Legal Capacity under the Convention on the Rights of Persons with Disabilities, 2012, 20 *Journal of Law and Medicine* 22.

Mechlem, Kerstin, 2009, Treaty Bodies and the Interpretation of Human Rights, 42 *Vanderbilt Journal of Transnational Law*.

Minkowitz, Tina, “The United Nations CRPD on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions” (2007) 34:2 *Syracuse J. Int'l L. & Com.* 405.

Nieminen, Liisa, 2005, Vammaisten henkilöiden ihmisoikeudet yleiseen ihmisoikeuskehykseen sijoitettuna, *Lakimies* 6/2005, 898–924.

Perlin, Michael L., 2013, Striking for the Guardians and Protectors of the Mind: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law, 117(4) *Penn State Law Review*.

Quinn, Gerard & Alston, Philip, 1987, The nature and Scope of States Parties' obligations under the International Covenant on Economic, Social and Cultural Rights, 9(2), *Human Rights Quarterly*.

Rachlisnki, Jeffrey J., 2011, Evidence-based law, 96(4) *Cornell Law Review*.

Salzman, Leslie, 2010, Rethinking guardianship (again): substituted decision making as a violation of the integration mandate of title II of the Americans with Disabilities Act, Cardozo Legal Studies, Research Paper No. 282, *University of Colorado Law Review*, 81.

Salzman, Leslie, 2011, Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative?, 4 *Saint Louis University Journal of Health Law & Policy* 279.

Silvers, Anita, & Francis, L.P., 2009, Thinking about the Good: Reconfiguring Liberal Metaphysics (or not) for People with Cognitive Disabilities, *Metaphilosophy* 40 (3–4).

Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, *Research and Practice in Intellectual and Developmental Disabilities*, published online 15 Oct 2015.

Stein, Michael A., 2007, Disability Human Rights, *California Law Review*, 95(1).

Stein, Michael A. & Lord, Janet E., 2010, Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities, and Future Potential, 32(3) *Human Rights Quarterly*.

Then, Shih-Ning, 2013, Evolution and innovation in guardianship laws: Assisted decision-making. *Sydney Law Review*, 35(1).

Weller, Penelope, 2009, Human Rights and Social Justice: The Convention on the Rights of Persons with Disabilities and the Quiet Revolution in International Law, *The Journal of Law and Social Justice* 4, 74-91.

Academic dissertations and theses

Arstein-Kerslake, Anna, 2014, Restoring voice to people: realizing the right to equal recognition before the law of people with Cognitive Disabilities, Doctoral Thesis in Law (PhD, Law), National University of Ireland, Galway (NUIG) Faculty of Business, Public Policy, and Law, July 2014.

Treaties, reservations, recommendations and preparatory work documents

United Nations, Vienna Convention on the Law of Treaties, 23 May 1969, United Nations, Treaty Series, vol. 1155, p. 331.

UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, United Nations, Treaty Series, vol. 1249, p. 13.

UN General Assembly, International Covenant on Civil and Political Rights, 16 December 1966, United Nations, Treaty Series, vol. 999, p. 171.

UN General Assembly, Convention on the Rights of Persons with Disabilities, 13 December 2006, A/RES/61/106, CRPD.

Recommendation No R(99)4 of the Committee of Ministers to member states on Principles Concerning The Legal Protection of Incapable Adults.

Preparatory work of the Convention on the Rights of Persons with Disabilities: <http://www.un.org/esa/socdev/enable/disparl.htm#ahcreport>.

Reservations and declarations to Article 12 of the CRPD: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en.

General comments and concluding observations of treaty bodies

UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1.

UN Human Rights Committee, General Comment No.31, Nature of the General Legal Obligation on States Parties to the Covenant, U.N. Doc. CCPR/C/21/Rev.1/Add.13 (2004).

Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Sweden, Committee on the Rights of Persons with Disabilities (CRPD), 11th Sess., UN Doc. CRPD/C/SWE/CO/1 (31 March–11 April 2014), available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fSWE%2fCO%2f1&Lang=en

United Nations Committee on the Rights of Persons with Disabilities, Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities: Peru, 7th sess, UN Doc CRPD/C/PER/CO/1 (16 May 2012), available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fPER%2fCO%2f1&Lang=en.

Foreign laws

The Adult Guardianship Act, RSBC 1996, c. 6 (Can.)
Representation Agreement Act, R.S.B.C. 1996, c. 405 (Can.)

National laws and regulations

The Act on Guardianship (34/1898)
The Guardianship Services Act (442/1999)
The Administrative Procedure Act (434/2003)
The Social Welfare Act (1301/2014)
The Act on the Status and Rights of Social Welfare Clients (812/2000)
The Act on the Status and Rights of Patients (785/1992)
The Act on Services and Assistance for the Disabled (1987/380)
The Act on the Interpreting Services for Persons with Disabilities (2010/133)
The Act on Special Care for Mentally Handicapped Persons (519/1977)

The Constitution of Finland (731/1999)

Preparatory work and other official publications

The Government Bill 146/1998 vp Hallituksen esitys eduskunnalle holhouslainsäädännön uudistamiseksi.

The Government Bill HE 284/2014 vp., Hallituksen esitys eduskunnalle vammaisten henkilöiden oikeuksista tehdyn yleissopimuksen ja sen valinnaisen pöytäkirjan hyväksymisestä sekä laeiksi yleissopimuksen ja sen valinnaisen pöytäkirjan lainsäädännön alaan kuuluvien määräysten voimaansaattamisesta ja eduskunnan oikeusasiamiehestä annetun lain muuttamisesta.

The Government Bill HE 19/2014 vp Hallituksen esitys eduskunnalle yhdenvertaisuuslaiksi ja eräiksi siihen liittyviksi laeiksi.

The Government Bill 96/2015 vp Hallituksen esitys eduskunnalle laiksi kehitysvammaisten erityishuollosta annetun lain muuttamisesta.

The Government Bill HE 108/2014 vp Hallituksen esitys eduskunnalle laiksi sosiaalihuollon asiakkaan ja potilaan itsemääräämisoikeuden vahvistamisesta ja rajoitustoimenpiteiden käytön edellytyksistä sekä eräiksi siihen liittyviksi laeiksi.

PeVL 15/2015 vp — HE 96/2015 vp (statement of the Constitutional law Committee)

KK 76/2015 vp (written question)

Table of cases and other decisions

KKO:2005:2

Decision of the Parliamentary Ombudsman 27.1.2012, dnro. 2709/4/10

Reports

Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario, available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>.

Bigby, C., Douglas, J., & Whiteside, M., 2015, Processes and dilemmas in support for decision-making. Report to Scope. Melbourne: Living with Disability Research Centre, La Trobe University On-Line Repository, available at: http://apo.org.au/files/Resource/final_full_report_for_support_for_decision_making_dilemmas_and_challenges_6_june_2015_0.pdf.

Hirvonen, Ari, Mitkä metodit? Opas oikeustieteen metodologiaan, Yleisen oikeustieteen julkaisuja, 17. Helsinki 2011, available at: http://www.helsinki.fi/oikeustiede/tutkimus_ja_julkaisut/julkaisut/yleinen_oikeustiede/hirvonen_mitka_metodit.pdf.

Kerzner, Lana, 2011, Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: a Canadian perspective. Prepared for In From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century. University of British Columbia, Canada April 2011, available at:

http://citizenship.sites.olt.ubc.ca/files/2014/07/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf.

Kumpuvuori, Jukka, Tuetun päätöksenteon kehittäminen Suomessa, Report to the Ministry of Social Affairs and Health, December 2010.

Quinn, G. & Degener, T., The Moral Authority for Change: Human Rights Values and the Worldwide Process of Disability Reform, in Guinn, G. et al. (Eds.), *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, Geneva: OHCHR 2002.

Sivula, Sirkka, 2010, Tuettu päätöksenteko ratkaisuna oikeusturvan ongelmiin, in Marja Pajukoski (Ed.) *Pääseekö asiakas oikeuksiinsa? Sosiaali- ja terveydenhuollon ulkopuoliset tekijät -työryhmä Raportti III*, p.111.

Other

A law proposal composed by the working group of the Ministry of Social Affairs and Health for the Act concerning special services of persons with disabilities: http://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/70354/URN_ISBN_978-952-00-3582-2.pdf?sequence=1.

A list of all the submissions on the draft General Comment of the CRPD Committee: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>.

A legal opinion on Article 12 which was written by an international group of legal academics: <http://disability-studies.leeds.ac.uk/files/library/legal-opinion-LegalOpinion-Art12-FINAL.pdf>.

Minkowitz, Tina, Submission to Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12, January 22, 2014, available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>.

Office of the United Nations High Commissioner of Human Rights (OHCHR), "Legal Capacity", Background Conference Document for the Sixth Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 1-12 August 2005.

Quinn, Gerard, Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD, Concept Paper, HPOD Conference, Harvard Law School, 20 February, 2010, available at: http://www.nuigalway.ie/cdlp/staff/gerard_quinn.html.

Submission by the Finnish National Human Rights Center (NHRI) on Article 12: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>.

UN Office of the High Commissioner for Human Rights (OHCHR), Foreword, Handbook for parliamentarians on the Convention on the Rights of Persons with disability: from exclusion to equality realizing the rights of persons with disabilities, 2007, HR /PUB/07/6.

Internet sources

Fact sheet about a Representation Agreement with Section 7 Standard Powers, Nidus personal Planning Resource Center and Registry, March 2012. Available at: http://www.nidus.ca/PDFs/Nidus_FactSheet_RA_Section7.pdf (accessed 01.01.2016).

Nidus, Personal Planning Resource Centre and Registry, http://www.nidus.ca/?page_id=238 (accessed 01.01.2016).

Vela Microboard Society of Canada, <http://www.velacanada.org/vela-microboards> (accessed 03.01.2016)

The reform of the disability legislation, the Ministry of Social Affairs and Health, <http://stm.fi/vammaislainsaadannon-uudistus> (accessed 30.03.2016).

Press release of the Government, 16.04.2015, http://valtioneuvosto.fi/artikkeli/-/asset_publisher/tyoryhma-ehdottaa-vammaiset-henkilot-saisivat-palvelut-toimintakyvyn-haitan-perusteella?_101_INSTANCE_3wyslLo1Z0ni_groupId=1271139 (accessed 12.02.2016).

Parliament, consideration of HE 96/2015 vp, https://www.eduskunta.fi/FI/vaski/KasittelytiedotValtiopaivaasia/Sivut/HE_96+2015.aspx (accessed 01.04.2016).

Parliament, LATI, ratification of the CRPD, https://www.eduskunta.fi/FI/tietoaeduskunnasta/kirjasto/aineistot/kotimainen_oikeus/LATI/Sivut/vammaisten-oikeuksien-yleissopimuksen-ratifiointi.aspx (accessed 15.03.2016).

Resources of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, <https://www.un.org/development/desa/disabilities/resources/ad-hoc-committee-on-a-comprehensive-and-integral-international-convention-on-the-protection-and-promotion-of-the-rights-and-dignity-of-persons-with-disabilities.html> (accessed 10.04.2016).

List of Abbreviations

CEDAW	The Convention on the Elimination of All Forms of Discrimination Against Women
CRPD	The Convention on the Rights of Persons with Disabilities
GSA	The Guardianship Services Act
ICCPR	The International Covenant on Civil and Political Rights
RAA	The Representation Agreement Act
SCMHA	The Act on Special Care for Mentally Handicapped Persons
UDHR	The Universal Declaration of Human Rights
VCLT	The Vienna Convention on the Law of Treaties

1. Introduction

1.1 The topicality of the issue

The right to self-determination and participation in society are at the core of the Convention on the Rights of Persons with Disabilities¹ (hereinafter CRPD). Legal capacity has been deprived of various different groups throughout history, but persons with disabilities continue to remain the subject of legal capacity denials all over the world.² Article 12 of the Convention endeavors to address this discriminatory practice by demanding equal recognition before the law.

Finland signed the CRPD and the Optional Protocol on 30.3.2007. The Convention has not entered into force in Finland for the time being, but the ratification process is at the final stage. On 4 December 2014, the Government submitted to Parliament a Government Bill (284/2014) on the ratification of the UN Convention on the Rights of Persons with Disabilities, and the Optional Protocol to the Convention. The Finnish Parliament passed the Act on 03.03.2015. According to the decision by Parliament, ratification will not be finalised until national legislation has been amended so that it is consistent with the Convention. This relates to the requirements of Article 14 of the CRPD and the deficits in the Finnish legislation, concerning persons with intellectual disabilities and their right to self-determination.³

The proposed Act on the Right to Self-Determination⁴ was intended to be enacted in order to bring the Finnish legislation regarding self-determination of persons with intellectual disabilities to the required level, but the legislative proposal lapsed as the previous Parliament did not consider it by the end of the electoral term mid-March 2015. As a temporarily solution to expedite the ratification process, the Ministry of Social Affairs and Health began to prepare amendments directly to the Act on Special Care for Mentally

¹ Article 3, Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006), available at <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>.

² UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.8.

³ See

https://www.eduskunta.fi/FI/tietoeduskunnasta/kirjasto/aineistot/kotimainen_oikeus/LATI/Sivut/vammaisten-oikeuksien-yleissopimuksen-ratifiointi.aspx.

⁴ Government Bill HE 108/2014 vp Hallituksen esitys eduskunnalle laiksi sosiaalihuollon asiakkaan ja potilaan itsemääräämisoikeuden vahvistamisesta ja rajoitustoimenpiteiden käytön edellytyksistä sekä eräiksi siihen liittyviksi laeiksi.

Handicapped Persons (519/1977).⁵ The Government introduced the Government Bill 96/2015⁶ on 22.10.2015 and it is currently under consideration in Parliament.⁷ The Constitutional Law Committee issued a statement on the Bill on 10.12.2015.⁸

The right to individual self-determination is in the center of many on-going reforms in the Finnish disability-related legislation at the moment. In addition to the proposed Act on the Right to Self-Determination and the amendments to the Act on Special Care for persons with Intellectual Disabilities, the Government is drafting a new Act (the Act concerning special services of persons with disabilities) which would combine the Act on Services and Assistance for the Disabled (1987/380) with the Act on Special Care for Mentally Handicapped Persons (519/1977). The proposed Act concerning special services of persons with disabilities has an objective to secure self-determination and the full participation of persons with disabilities in society. The drafting of this Act will continue in the spring 2016 and the aim is to submit the Government Bill to Parliament in autumn 2017.⁹ Article 12 of the CRPD is closely related to these reforms.

Broadly speaking, disability had been invisible in international human rights law until the adoption of the CRPD.¹⁰ The CRPD and its Optional Protocol were adopted on 13 December 2006, and opened for signature on 30 March 2007. After the 20th ratification the convention entered into force on 3 May 2008.¹¹ The Convention can be considered as ground-breaking in multiple ways. It is the first convention which specifically addresses the human rights of people with disabilities.¹² It is also the first human rights treaty of the third millennium and the first human rights convention to be open for signature by regional integration organizations. The European Union ratified the CRPD on 23 December 2010.

⁵ See

https://www.eduskunta.fi/FI/tietoeduskunnasta/kirjasto/aineistot/kotimainen_oikeus/LATI/Sivut/vammaisten-oikeuksien-yleissopimuksen-ratifiointi.aspx accessed on 14.4.2016; and written question KK 76/2015 vp https://www.eduskunta.fi/FI/vaski/KasittelytiedotValtiopaivaasia/Sivut/KK_76+2015.aspx

⁶ Government Bill HE 96/2015 vp laiksi kehitysvammaisten erityishuollosta annetun lain muuttamisesta.

⁷ For more information, see

https://www.eduskunta.fi/FI/vaski/KasittelytiedotValtiopaivaasia/Sivut/HE_96+2015.aspx.

⁸ Constitutional Law Committee PeVL 15/2015 vp.

⁹ For more information, see <http://stm.fi/vammaislainsaadannon-uudistus>.

¹⁰ Kayess, R. & French, P., Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities, *Human Rights Law Review*. 8:1, Oxford University Press. 2008, p.12.

¹¹ See <https://www.un.org/development/desa/disabilities/resources/ad-hoc-committee-on-a-comprehensive-and-integral-international-convention-on-the-protection-and-promotion-of-the-rights-and-dignity-of-persons-with-disabilities.html>.

¹² Weller, Penelope, 2009, Human Rights and Social Justice: The Convention on the Rights of Persons with Disabilities and the Quiet Revolution in International Law, *The Journal of Law and Social Justice* 4, p.83; Stein, M.A. & Lord, J.E., 2009, Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities, in Arnardóttir, O.M. & Quinn, G. (Eds.), 2009, *the UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff, p.17.

The CRPD is a human rights instrument with an explicit, social development dimension. It embraces a broad definition of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. In addition, it clarifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights.¹³ The Convention is monitored by the Committee on the Rights of Persons with Disabilities.¹⁴

1.2 Theoretical approaches to disability

Disability has been defined by different theories over time. The medical model of disability focuses on the persons' impairments and limitations with the intention to reduce them and to rehabilitate the person. Disability is perceived as a completely individual problem.¹⁵ The first international resolutions concerning persons with disabilities were based on the medical approach to disability.¹⁶ Therefore, human rights of persons with disabilities received little attention and the period of institutionalisation prevailed in societies.¹⁷

In the social model, disability is seen as a result of the interaction between people living with impairments and an environment which is filled with physical, attitudinal, communication and social barriers. This model brings the implication that these environmental barriers must change to enable people living with impairments to participate in society on an equal basis with others. Disability is understood as socially constructed resulting from the society's inability to accommodate its environment to persons with disabilities. Furthermore, the person herself is located at the centre instead of her impairment and disability is seen as an element of society's diversity.¹⁸ The social

¹³ For a discussion on equality and the CRPD, see e.g. Kumpuvuori, J., & Scheinin, M. (2009); and Kayess, R. & French, P., *Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities*, *Human Rights Law Review*. 8:1, Oxford University Press. 2008.

¹⁴ Stein, Michael A. & Lord, Janet E., 2010, Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities, and Future Potential, 32(3) *Human Rights Quarterly*.

¹⁵ See Quinn, G. & Degener, T., The Moral Authority for Change: Human Rights Values and the Worldwide Process of Disability Reform, in Guinn, G. et al. (Eds.), *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, Geneva: OHCHR 2002, p.14; see also Smith, Steven R., 2009, Social Justice and Disability; Competing interpretations of the medical and social models, in Kristjana Kristiansen, Simo Vehmas, & Tom Shakespeare, (Eds.), *Arguing about Disability: Philosophical Perspectives*, New York: Routledge, pp.15-30.

¹⁶ Stein, Michael Ashley, 2007, Disability Human Rights, *California Law Review* 95(1), pp.87-88.

¹⁷ See Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 *Sydney Law Review*, pp.136-137.

¹⁸ See Shakespeare, Tom, The Social Model of Disability, in Davis, Lennard J. (Ed.) in *Disability Studies Reader*, New York: Routledge, pp.214-222; Vehmas (2005), pp.109-146.

explanations of disability have been conceptualized in several ways around the world.¹⁹ In Britain the model has been used to analyse the social barriers and exclusion, which persons with disabilities encounter in society,²⁰ whereas in North-America it has been adopted in terms of minority rights and civil rights.²¹ The Nordic countries, on the other hand, approach disability through a relational understanding.²²

The human rights approach to disability builds on the social approach by considering persons with disabilities as subjects of rights and locating the “problem” of disability outside the person. It concentrates on the inherent dignity of every human being and to secure the respect for their equal rights. The human rights model treats barriers in society as discriminatory and seeks ways to create conditions which would allow full participation by persons with disabilities.²³

1.3 The CRPD and a new conception of personhood

The attribution of incapacity to persons with disabilities occur in the contexts of status model, outcome model and functional model. The status based approach entails that having a certain impairment (usually loss of cognitive capacity or mental illness) equates incapacity to make decisions in some or all areas of life. The individual’s actual capacities are irrelevant. The outcome-based approach focuses on a person’s previous decisions and evaluates them according to their compatibility with societal values. The attribution of incapacity is, thus, made on the grounds of the reached decision by the person with disabilities. The functional approach emerged in the 1990s. It endeavors to assess a person’s ability to understand the nature and consequences of a certain decision at a specific point in time. An impairment is applied as a required precondition, but it is not a legitimate ground, per se, for the denial of legal capacity. The functional approach allows substituted decision-making in limited circumstances and with appropriate safeguards. All three approaches share some characteristics, such as a medical diagnosis and the

¹⁹ Traustadóttir, Rannveig, Disability Studies, the Social Model and Legal Developments, in Arnardóttir, O.M. & Quinn, G. (Eds.), 2009, *the UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff, p.3-4.

²⁰ Mallet, R. & Runswick-Cole, K., 2014, *Approaching Disability*, NY: Routledge, Taylor and Francis eBooks, Web, pp.5, 8- 11.

²¹ Ibid., at pp.22-25.

²² See Gustavsson, A., Tøssebro, J., & Traustadóttir, R., (2005), Introduction: Approaches and perspectives in the Nordic disability research, in a Gustavsson, A., Sandvin, J., Traustadóttir, R., & Tøssebro, J. (Eds.), *Resistance, reflection, and change: Nordic disability research*, Lund: Studentlitteratur, pp. 23-39. For a discussion of the differences between the British model and the Nordic model of disability, see supra note 20, at pp.20-22.

²³ Quinn, G. & Degener, T., supra note 15, at p.14; See also Stein, Michael Ashley, 2007, *Disability Human Rights*, *California Law Review* 95(1).

reliance on mental capacity assessment, but the functional model is clearly an improvement compared to the previous approaches.²⁴

Gerard Quinn believes that conceptions of personhood are the real reason behind the debate regarding Article 12 of the CRPD.²⁵ Liberal-democratic foundationalism assumes persons to be rational agents.²⁶ Our political discourse is founded on the idea of a social contract for mutual advantage. Furthermore, traditional human rights thinking perceives persons as self-sufficient and autonomous individuals.²⁷ In a world conceptualized in terms of a social bargain, persons who are dependent of others are not considered as full participants.²⁸ Contemporary moral philosophers²⁹ have endeavored to include persons with cognitive disabilities into theories of justice in order to create a holistic concept of personhood.³⁰ This thesis adopts the “inclusive model of autonomy” created by Laura Davy, that is based on two premises: i) autonomy is understood as a potentiality which can be nurtured and enabled in persons throughout their life ii) and the exercise of autonomy requires supportive social relationships and structures which enable autonomy.³¹

The CRPD represents a remarkable new development in international human rights law with respect to the rights of an individual within society. Therefore, the Convention’s

²⁴ Quinn, G. & Arstein-Kerslake, A., (2012), Restoring the “human” in “human rights”, in Gearty, C. & Douzinas, C. (Eds.), *Cambridge Companion to Human Rights Law*, Cambridge: Cambridge University Press, pp.44-46; Dhand, Amita, 2007, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?, 34 *Syracuse Journal of International Law and Commerce* 429, pp.431-433; Booth Glen, Kristin, 2012, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, *Columbia Human Rights Law Review*, 44. See also UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.15.

²⁵ See Quinn, Gerard, Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD, HPOD Conference, Harvard Law School, 20 February, 2010.

²⁶ See Ibid.; Quinn, G. & Arstein-Kerslake, A., (2012), Restoring the “human” in “human rights”, in Gearty, C. & Douzinas, C. (Eds.), *Cambridge Companion to Human Rights Law*, Cambridge: Cambridge University Press, p.41.

²⁷ See e.g. Rawls (2005).

²⁸ Petman, Jarna, 2009, The Special Reaching for the Universal: Why a Special Convention for Persons with Disabilities?, in Kumpuvuori, J., & Scheinin, M. (Eds.), *United Nations Convention on the Rights of Persons with Disabilities – Multidisciplinary Perspectives*, Helsinki: The Center for Human Rights of Persons with Disabilities in Finland (VIKE), pp.23-24; See generally Arstein-Kerslake, Anna, 2014, Restoring voice to people: realizing the right to equal recognition before the law of people with Cognitive Disabilities, Doctoral Thesis in Law (PhD, Law).

²⁹ See Kittay (1999); Wong, S. I, 2010, Duties of Justice to Citizens with Cognitive Disabilities, In *Cognitive Disability and its Challenge to Moral Philosophy*, edited by E. F. Kittay and L. Carlson. Chichester: Wiley-Blackwell; Silvers, Anita, & Francis, L.P., 2009, Thinking about the Good: Reconfiguring Liberal Metaphysics (or not) for People with Cognitive Disabilities, *Metaphilosophy* 40 (3–4); Nussbaum, Martha, 2006, *Frontiers of Justice: Disability, Nationality, Species Membership*, Cambridge, MA: Harvard University Press.

³⁰ Flynn, E. & Arstein-Kerslake, A., 2014, 'Legislating Personhood: Realizing the Right to Support in Exercising Legal Capacity', *International Journal of Law in Context*, 10(1), p.84.

³¹ Davy, Laura, 2015, Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory, *Hypatia* 30(1).

significance extends beyond merely disability rights. The CRPD embodies the understanding that many persons with disabilities are not self-sufficient and depend upon the support from others to be able to exercise their rights.³² Moreover, the Convention can be perceived to be founded on relational autonomy³³ and thus challenge the “myth system of personhood” in the traditional human rights thinking.³⁴ The CRPD provides a perception of personhood which does not give primacy to rationality and recognizes the interdependence of all individuals.³⁵ The ability to live an autonomous life is not dependent on mental capacity, but on the resources available to a person.³⁶

1.4 Research questions and methodology

Human rights of persons with disabilities have not raised a lot of interest among legal scholars in Finland.³⁷ This thesis aims to fill this research gap by examining the right to equal recognition before the law as regulated in Article 12 of the CRPD from the perspective of persons with intellectual disabilities. In addition, the objective is to analyse whether the Finnish legislation is compatible with the requirements of Article 12. The Convention has not yet entered into force in Finland, which signifies that the review will be realized with the intention to assess what changes would be required to be made in the relevant Finnish legislation after the treaty has been ratified.

The first wave of legal reform concerning regimes of guardianship occurred in the mid-1970s. Since then, subsequent waves of reform have developed and the new paradigm shift in legal capacity embodied by the CRPD can be considered as the current wave.³⁸ After having established the meaning and scope of Article 12, this thesis will investigate

³² See O’Cinneide, Colm, 2009, Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities, in Arnardóttir, O.M. & Quinn, G. (Eds.), *the UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff, pp.164-168; Dimopoulos, Andreas, 2010, Issues in Human Rights Protection of Intellectually Disabled Persons, Burlington, VT: Ashgate, pp.29-46.

³³ Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario, pp.38-41.

³⁴ Quinn, G. & Arstein-Kerslake, A. supra note 24, at p.40; Arstein-Kerslake, Anna supra note 28, at pp.38-76.

³⁵ Quinn, G. & Arstein-Kerslake supra note 24, at pp.52-53; O’Cinneide, Colm supra note 32, at, pp.164-168; Dimopoulos, Andreas supra note 32, at pp.29-46.

³⁶ Degener, Theresia, 2003, Disability as a Subject of International Human Rights Law and Comparative Discrimination Law, in Herr, S.S, Gostin, L.O., Koh,H.H. (Eds.), *The Human Rights of Persons with Intellectual Disabilities: Different but equal*, Oxford, UK: Oxford University Press, p.154.

³⁷ Nieminen, Liisa, 2005, Vammaisten henkilöiden ihmisoikeudet yleiseen ihmisoikeuskehykseen sijoitettuna, *Lakimies* 6/2005, p.905.

³⁸ See Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 Sydney Law Review.

further the new wave of reform by providing a critical analysis of the system of supported decision-making. The research questions are as follows:

- What is the normative content of Article 12 of the CRPD?
- What is a system of supported decision-making envisioned in Article 12(3)?
- Is the existing Finnish legislation compatible with the requirements of Article 12 regarding persons with intellectual disabilities?

The first part of this paper analyzes the interpretation of Article 12 and the obligations it sets out to States parties. Thereafter, the research elaborates further into the system of supported decision-making with the intention to clarify the requirements and challenges of this new support model. The third part focuses on the Finnish legal order and the Guardianship Services Act in relation to Article 12 of the CRPD. The research ends with final conclusions from the material.

The methodology for this thesis is mainly doctrinal.³⁹ The research questions require a pure legalistic analysis of the interpretation of the text of Article 12 as well as systematization of the research material. For this purpose, the travaux préparatoires of the Convention, published documents of the CRPD Committee and writings of scholars will be used as source material in chapters 2 and 3. The contents of existing legislation in Finland are examined in chapter 4 by investigating Acts, Governments Bills, legal practice and writings of legal scholars. A comprehensive comparative law methodology is not applied, but the Canadian Province of British Columbia is used as an example of good practices that exist in the field of supported decision-making. This thesis includes also *de lege ferenda* research in the chapters 4 and 5, which seek to provide recommendations for future legislation.

Additionally, research is undertaken in the field of disability studies in order to understand the main theories of disability, and to be able to locate this thesis in the wider context of the social and human rights model of disability. In the same vein, an examination into moral philosophy with respect to cognitive disability, and the granting of personhood, is

³⁹ See Aarnio (1978); Timonen (1998); Hirvonen, Ari, Mitkä metodit? Opas oikeustieteen metodologiaan, Yleisen oikeustieteen julkaisu, 17. Helsinki 2011, available at: http://www.helsinki.fi/oikeustiede/tutkimus_ja_julkaisut/julkaisut/yleinen_oikeustiede/hirvonen_mitka_meto_dit.pdf.

undertaken in order to comprehend the deeper layers of the paradigm shift in legal capacity. As stated previously, this thesis is based on an inclusive model of autonomy.⁴⁰

1.5 The scope of the research

This thesis seeks to specifically address the perspective of intellectual disabilities in relation to Article 12 of the CRPD. However, most of the research findings are applicable also to other cognitive disabilities and mental disabilities. It is worth noting, that the Convention does not limit itself to any set disability, as Article 12 includes all disabilities that fit into the scope of Article 1 of the Convention. The right to self-determination is a broad concept and covers many other areas besides the right to equal recognition before the law. Due to the limited space for a master's thesis, this thesis concentrates on legal capacity and the right to make choices about one's own life.

For the same reason, legal capacity in the European Union, legal capacity in other international conventions apart from the CRPD, and the case law of the European Court of Human Rights on legal capacity, are excluded from the scope of this paper. The main focus is on the interpretation of Article 12 of the CRPD and its implementation to the Finnish legal order. The review of the Finnish legislation will mainly concentrate on the Guardianship Services Act 442/1999, which is the main Act regulating the Finnish regime of guardianship. The scope of this thesis is limited to the civil context. Issues relating to legal capacity in criminal law of persons with cognitive and mental disabilities are left for future research.

⁴⁰ See Laura Davy, *supra* note 31.

2. The right to equal recognition before the law (Article 12 CRPD)

2.1 General overview

The wording of Article 12 – ‘Equal recognition before the law’ - is as follows:

- 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*
- 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
- 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.*
- 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.*
- 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.⁴¹*

The right to equal recognition before the law is not only a right itself, but also a necessary prerequisite to all other rights. Without the recognition before the law, a person's rights cannot be protected by the legal system and individuals cannot perform legal transactions, such as entering into contracts or create and end legal relationships.⁴² The deprivation of

⁴¹ Article 12, CRPD.

⁴² UN Office of the High Commissioner for Human Rights (OHCHR), Foreword, Handbook for parliamentarians on the Convention on the Rights of Persons with disability: from exclusion to equality realizing the rights of persons with disabilities, 2007, HR/PUB/07/6, p.23-24; Quinn, G. & Arstein-Kerslake, A., (2012), Restoring the “human” in “human rights”, in Gearty, C. & Douzinas, C. (Eds.), *Cambridge Companion to Human Rights Law*, Cambridge: Cambridge University Press, p.42; UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.12.

legal capacity has resulted in various cases to the denial of fundamental rights, such as the right to liberty; and the right to give and refuse consent to medical treatment and intimate relationships.⁴³ Legal capacity is, as Quinn and Arstein-Kerslake state, “the legal tool by which people exercise their moral agency in the world.”⁴⁴ Therefore, losing one’s legal capacity can have disastrous consequences for the individual. Incapacity usually leads to weakened self-determination about one’s life, as decisions are being made for the individual by a third party either informally or through limited/plenary guardianship.⁴⁵

Article 12 is one of the most contentious⁴⁶ and revolutionary articles in the CRPD.⁴⁷ It represents a shift from the traditional binary determination of capacity and incapacity to an approach to legal capacity that is based on equality.⁴⁸ This is a significant legal change for people with disabilities. It is not about creating a different legal status of people with disabilities, but instead conceptualizing a legal status that applies equally to everyone – to people with disabilities as well as to people without disabilities.⁴⁹ The disability rights movement from the mid-twentieth century onwards concentrated mainly on prohibiting discrimination on the basis of disability and securing socio-economic rights. The adoption of the CRPD in 2006 brought global attention to the right to legal capacity of persons with disabilities.⁵⁰ It is important to acknowledge that legal capacity denials do not solely occur through substituted decision-making or by imposing adult guardianship on a person.⁵¹ Involuntary treatment⁵² and situations where an individual is seen as

⁴³ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.8.

⁴⁴ Quinn, G. & Arstein-Kerslake, A., (2012), Restoring the “human” in “human rights”, in Gearty, C. & Douzinas, C. (Eds.), *Cambridge Companion to Human Rights Law*, Cambridge: Cambridge University Press, p.42

⁴⁵ Ibid., at p.42.

⁴⁶ The controversial nature of Article 12 can be observed by the various reservations and declarations it has generated. See a complete list: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtsg_no=IV-15&chapter=4&lang=en (accessed 16 October 2015).

⁴⁷ Dhanda, Amita, 2006–2007, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?, *Syracuse Journal of International Law and Commerce* 34, pp.438-456.

⁴⁸ Minkowitz, Tina, “The United Nations CRPD on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions” (2007) 34:2 *Syracuse J. Int’l L. & Com.* 405 at 408.

⁴⁹ Arstein-Kerslake, Anna & Flynn, Eilionóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, 20(4) *The International Journal of Human Rights*, p.15.

⁵⁰ Ibid., at p.1.

⁵¹ Ibid., at p.11

⁵² See Minkowitz, Tina, 2006-2007, The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions, 34 *Syracuse Journal of International Law & Commerce* 405.

incompetent to testify or found not guilty on the ground of insanity⁵³ are examples of deprivations of legal capacity outside the scope of substituted decision-making.⁵⁴

The negotiations of Article 12 did not progress straightforwardly.⁵⁵ Dhanda argues that it was due to the challenging of “some deeply held beliefs on human choice and freedom” during the drafting process.⁵⁶ The differing views in the negotiations of the contents of Article 12 of the CRPD are seen in the various interpretations adopted of the text of Article 12 among states parties. The contentious issue concerns the role of supported decision-making in relation to substituted decision-making. Some scholars consider that Article 12 obligates states parties to replace substituted decision-making with a system of supported decision-making, whereas other scholars view that supported decision-making regime should co-exist with substituted decision-making.⁵⁷

2.2 The history of the right to equal recognition before the law

The right to equal recognition before the law first appeared in Article 6 of the Universal Declaration of Human Rights (UDHR).⁵⁸ The International Covenant on Civil and Political Rights (ICCPR) included the right to equal recognition before the law in its Article 16 that states, almost identically with Article 6 of the UDHR, that “everyone shall have the right to recognition everywhere as a person before the law”.⁵⁹ Article 6 of the UDHR, Article 16 of the ICCPR and Article 15 of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) can be seen as the source of the right to equal recognition before the law in Article 12 of the CRPD.⁶⁰ Neither Article 6 of the UDHR nor

⁵³ See Minkowitz, Tina, 2014, Rethinking criminal responsibility from a critical disability perspective: The abolition of insanity/incapacity acquittals and unfitness to plead, and beyond, 23(3) *Griffith Law Review*, pp.434-466.

⁵⁴ Arstein-Kerslake, Anna & Flynn, Eilíonóir supra note 49, at p.11.

⁵⁵ All the reports, statements, summaries and other relevant materials of the eight sessions of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities are available at: <http://www.un.org/esa/socdev/enable/rights/adhoccom.htm>.

⁵⁶ Dhanda, Amita supra note 47, at p.457.

⁵⁷ Carney, Terry & Beupert, Fleur, 2013, Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making, 36 *University of New South Wales Law Journal* 175, p.181

⁵⁸ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, Vol.5, p.94-95.

⁵⁹ Article 16, ICCPR. UN General Assembly, *International Covenant on Civil and Political Rights*, 16 December 1966, United Nations, Treaty Series, vol. 999, p. 171.

⁶⁰ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.94-95.

Article 16 of the ICCPR elaborate more profoundly on the content of the right to equal recognition before the law. The monitoring body to the ICCPR, the Human Rights Committee, has not published a general comment on Article 16, and Article 16 has received little attention in the case law of the Human Rights Committee.⁶¹ Some aid for interpretation can be found in the preparatory work from the drafting process of this Article which strongly indicates that it contains solely the right to legal personhood without the capacity to act.⁶²

The right to equal recognition before the law was later further evolved in 1979 when the CEDAW was adopted by the UN General Assembly.⁶³ Article 15 of the CEDAW aims to ensure women's legal capacity by reaffirming women's equality with men before the law, and requiring that States parties accord to women legal capacity on an equal basis with men in civil law matters and the "same opportunities to exercise that capacity."⁶⁴ Moreover, it particularly mentions the rights to equality in relation to concluding contracts, administering property and judicial procedures. Article 15 covers both the right to be a person before the law (holder of rights) as well as the right to exercise legal capacity on an equal basis (legal capacity to act).⁶⁵

Article 12 of the CRPD was regulated 28 years later from the adoption of the CEDAW. It can be regarded as a yet more evolved version of the right to equal recognition before the law. Article 12 of the CRPD is groundbreaking as it introduces the right to access to support to exercise legal capacity which has never before been included in an international human rights instrument.⁶⁶ The CRPD illustrates an alternative way of understanding legal

⁶¹ Office of the United Nations High Commissioner of Human Rights (OHCHR), "Legal Capacity", (Background Conference Document for the Sixth Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 1-12 August 2005), para.8.

⁶² Bossuyt, Marc J., 1987, Guide to the "Travaux Préparatoires" of the International Covenant on Civil and Political Rights, Martinus Nijhoff, pp. 335 ff.

⁶³ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.94-95.

⁶⁴ Article 15, CEDAW. UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, United Nations, Treaty Series, vol. 1249, p. 13.

⁶⁵ Office of the United Nations High Commissioner of Human Rights (OHCHR), "Legal Capacity", (Background Conference Document for the Sixth Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 1-12 August 2005), para.18-21; Gooding, Piers, 2015, Navigating the "Flashing Amber Lights" of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, Human Rights Law Review (accepted for publication), p.6.

⁶⁶ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.95.

capacity by acknowledging that requiring support to exercise legal capacity does not signify incapacity. The Convention can be expected to lead to a paradigm shift in thinking on legal capacity all over the world.⁶⁷

2.3 Treaty interpretation in international law

The rules of treaty interpretation in international law are codified in section 3 of the Vienna Convention on the Law of Treaties (VCLT).⁶⁸ Article 31 of the VCLT provides the general rule of interpretation which states that “a treaty shall be interpreted in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in the light of its object and purpose.”⁶⁹ Consequently, a narrow reading of the text of a treaty would not be compatible with Article 31 of the VCLT.⁷⁰ In cases where the terms of a treaty raise questions regarding their ordinary meaning, it can be confirmed by reference to a dictionary or relying on the common usage of the term. The “context” of a treaty is explained in the Vienna Convention as comprising the whole text (including its preamble and annexes) along with other agreements and instruments made by treaty parties concerning the treaty in question.⁷¹ The subjective perspective to treaty interpretation is covered by provision 4 of Article 31 stating that “a special meaning shall be given to a term if it is established that the parties so intended.”⁷²

In addition to the general rule of interpretation, the VCLT contains also supplementary means of interpretation in Article 32. When the interpretation under Article 31 would require to be confirmed or results “ambiguous or obscure” or “leads to a result which is manifestly absurd or unreasonable”, the usage of “supplementary means of interpretation, including the preparatory work of the treaty and the circumstances of its conclusion” is accepted.⁷³ There is a general agreement that the interpretation of human rights treaties by

⁶⁷ See, e.g. Perlin, Michael L., 2013, Striking for the Guardians and Protectors of the Mind: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law, 117(4) *Penn State Law Review*, p.1176.

⁶⁸ United Nations, *Vienna Convention on the Law of Treaties*, 23 May 1969, United Nations, Treaty Series, vol. 1155, p. 331, (hereinafter the Vienna Convention).

⁶⁹ Article 31, Vienna Convention on the Law of Treaties.

⁷⁰ Arstein-Kerslake, Anna, 2015, A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, pp.78-80.

⁷¹ Article 31(2), VCLT.

⁷² Article 31(4), VCLT.

⁷³ Article 32, Vienna Convention on the Law of Treaties.

the treaty bodies is not binding as such on States parties.⁷⁴ Nevertheless, these views are considered as “authoritative interpretations” of the respective treaties and the Committees are granted the power to determine possible failures to comply with the treaty. Therefore, the views of the treaty bodies cannot be perceived as merely recommendations. In fact, there are various convincing arguments in favor of the view that States parties are required to respect and enforce the interpretation adopted by the monitoring bodies.⁷⁵

The obligation of *pacta sunt servanda* in Article 26 of the VCLT contains that once a treaty has entered into force in a State party, the treaty is binding and must be performed by the State in good faith.⁷⁶ It can be argued that by having accepted the procedure of individual communications and the establishment of a monitoring body to the treaty concerned, a State party has accepted as well the implicit obligation to comply with the interpretations and recommendations issued by the monitoring body.⁷⁷ Consequently, the rejection of the interpretation formulated by the Committee can be regarded as a State’s bad faith attitude towards the obligations set out in the treaty.⁷⁸

Additionally, Article 4 of the CRPD regulates specific obligations that States parties are required to undertake, which all endeavor to ensure the full recognition and realization of the rights enumerated in the CRPD. Therefore, States parties are expected to remedy possible violations of the Convention as found by the Committee on the Rights of Persons with Disabilities (CRPD Committee). Moreover, Article 37 of the CRPD provides that States parties are required to cooperate with the Committee. On the basis of these elaborations, the legal nature of the interpretation adopted by the CRPD Committee on Article 12 of the CRPD⁷⁹ can be considered to have in practice greater force than purely recommendatory.

⁷⁴ Keller, H., Ulfstein, G., Grover, L., 2012, UN Human Rights Treaty Bodies. Law and Legitimacy, Cambridge: Cambridge University Press, pp.407-408; Tomuschat (2008), p. 220; Mechlem, Kerstin, 2009, Treaty Bodies and the Interpretation of Human Rights, 42 *Vanderbilt Journal of Transnational Law*, p.906.

⁷⁵ See e.g. Hanski, R. & Scheinin, M., 2007, Leading Cases of the Human Rights Committee, 2nd revised edition, Turku: Institute for Human Rights, Åbo Akademi University, p. 23; Keller, H., Ulfstein, G., Grover, L. supra note 74, at pp. 92-100.

⁷⁶ See also Human Rights Committee, General Comment 31, Nature of the General Legal Obligation on States Parties to the Covenant, U.N. Doc. CCPR/C/21/Rev.1/Add.13 (2004).

⁷⁷ Hanski, R. & Scheinin, M. supra note 75 p. 23.

⁷⁸ See S. Joseph, J. Schultz & M. Castan, 2004, The International Covenant on Civil and Political Rights: Cases, Materials and Commentary, 2nd Edition, Oxford University Press, pp. 24-25; Tomuschat (2008), p. 220.

⁷⁹ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1.

2.4 Interpretation of the text of Article 12 of the CRPD

Following from the examination of the Vienna Convention, the interpretation of Article 12 of the CRPD should begin with an investigation of the object and purpose of the CRPD. When analyzing the text of Article 12 itself, it is important to interpret it in relation to the other articles in the CRPD as its meaning cannot be understood in a vacuum. The purpose of the CRPD is to ““promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote and respect for their inherent dignity.”⁸⁰ The preamble sets out that the Convention is a human rights treaty from a disability perspective and it outlines the need to protect the human rights also of persons who require intensive support.⁸¹ The importance of the right to make one’s own decisions is highlighted separately in the section *n* of the preamble. The CRPD is founded on a social model of disability⁸² as well as on a human rights model.⁸³

A highly important aspect to understanding the totality of the CRPD is to comprehend the paradigm shift embodied by the Convention about the way persons with disabilities are perceived by the world.⁸⁴ The paradigm shift has begun around the world around a decade ago and the CRPD represents its crystallization. Taking this context into account, the purpose of the Convention is not solely to reform the laws and policies that are incompatible with it, but to “change the process itself to the point that disability is seen as an issue of justice.”⁸⁵ This profound shift is closely related to the move from a charity/medical model of disability to a human rights model where the person with a disability is recognized as a rights holder and an active subject of law. Governments are expected to take measures to foster inclusive societies which accommodate the variety in

⁸⁰ Article 1, UN General Assembly, Convention on the Rights of Persons with Disabilities, 13 December 2006, A/RES/61/106, CRPD.

⁸¹ Preamble (j), CRPD.

⁸² Article 1, CRPD.

⁸³ Stein, Michael A., 2007, Disability Human Rights, *California Law Review*, 95(1), p.76.

⁸⁴ See e.g., Quinn, Gerard, Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD, Harvard Project on Disability Conference, Harvard Law School, 20 February, 2010; Flóvenz, Brynhildur G., 2009, The Implementation of the UN Convention and the Development of Economical and Social Rights as Human Rights, in Arnardóttir, O.M. & Quinn, G. (Eds.), 2009, *the UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff, p.259; Perlin, Michael L., 2013, Striking for the Guardians and Protectors of the Mind: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law, 117(4) *Penn State Law Review*, pp.1159-1337.

⁸⁵ Arnardóttir, O.M. and Quinn, G. (Eds.), 2009, Introduction, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Boston: Martinus Nijhoff, p.xvii-xviii.

human characteristics.⁸⁶ This obligation is not rested on empathy and goodwill of the society, but on the respect for the human rights of persons with disabilities.

According to the Vienna Convention, the “ordinary meaning” of the text of Article 12 should be interpreted in the light of the object and purpose of the CRPD.⁸⁷ In other words, the ordinary meaning of the language in Article 12 can be found through the lenses of Article 1 of the CRPD (its purpose), the preamble and comprehending the paradigm shift which is the soul of the Convention. Some legal scholars, in fact, assert that Article 12 is the very “embodiment” of the paradigms shift.⁸⁸ The first observation that can be made from Article 12 is that as the title of the Article is “Equal recognition before the law”, it can be argued that it is the core right in Article 12 and other rights regulated within the Article are solely derivative of this right.⁸⁹ Therefore, the right to support in the exercise of legal capacity has been included in Article 12 in order to ensure that also individuals who have difficulties with exercising their legal capacity can enjoy their right to equal recognition before the law.

The first paragraph of Article 12 of the CRPD is formed in a similar manner as Article 6 of the UDHR and Article 16 of the ICCPR, stating:” States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.”⁹⁰ Using the term “reaffirm” implies that the provision does not establish any new rights, but restates what has been declared in the UDHR and the ICCPR. The difference between these two previous enumerations of this right and Article 12(1) of the CRPD is that Article 12(1) includes the term “person”. Paragraph 1 of the CRPD can, in fact, be interpreted to specifically refer to legal personality. Legal personality is defined in the Black’s Law Dictionary as “the particular device by which the law creates or recognizes units to which it ascribes certain powers and capacities.”⁹¹ Legal personality is essential for a person to be

⁸⁶ Carbert, Anne & Rioux, Marcia, 2003, Human Rights and Disability: The International Context, *Journal on Developmental Disabilities* 10(2), p.11; Kanter, Arlene S., 2007, The promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities, 34(2) *Syracuse Journal of International Law and Commerce*, p.291.

⁸⁷ Article 31, Vienna Convention on the Law of Treaties.

⁸⁸ See Quinn, G. & Arstein-Kerslake, A., (2012), Restoring the “human” in “human rights”, in Gearty, C. & Douzinas, C. (Eds.), *Cambridge Companion to Human Rights Law*, Cambridge: Cambridge University Press, pp.36-55.

⁸⁹ See Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.84.

⁹⁰ Article 12(1), CRPD.

⁹¹ Garner, Bryan A. (Ed.), 1999, *Black’s Law Dictionary*, 7th Edition, West Group, p.1163.

granted legal capacity and Article 12(1) can therefore be interpreted to guarantee legal personality to every human being.⁹²

The second paragraph of Article 12 regulates that “States parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”⁹³ The right to legal capacity on an equal basis was first established in Article 15 of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) in 1979. As mentioned above, Article 15 of the CEDAW includes both the capacity to be a holder of rights as well as legal capacity to act under the law. There is no reason to assume that Article 12(2) of the CRPD would have been regulated with a different intention in mind. This argument is supported by other provisions of Article 12, such as paragraph 5, which grants the right to act under the law to own and inherit property as well as to control one’s own financial affairs. Moreover, when taking the object and purpose of the CRPD into account, this is the only suitable interpretation.⁹⁴

An examination into the travaux préparatoires of Article 12 shows that in the final session of the Ad Hoc Committee, a footnote appeared to Article 12(2) which intended to restrict the concept of legal capacity to include solely the capacity to be a holder for rights in three of the U.N. languages.⁹⁵ The exclusion of this footnote from the treaty confirmed the negotiators’ intent to guarantee universal legal capacity without restrictions and, thus, to contain also the legal capacity to act.⁹⁶ The CRPD Committee affirmed this conclusion in its General Comment on Article 12.⁹⁷

The verb “recognizes” that is used in Article 12(2) of the CRPD has been understood as demanding more active obligation on States parties than, for example, using the verb

⁹² UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.11.

⁹³ Article 12(2), CRPD.

⁹⁴ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.85-86; See also a legal opinion on Article 12 which was written by an international group of legal academics, available at: <http://disability-studies.leeds.ac.uk/files/library/legal-opinion-LegalOpinion-Art12-FINAL.pdf> (last accessed 02.04.2016).

⁹⁵ For a discussion on the controversial footnote, which resulted in a number of reservations to Article 12, see Dhanda, Amita, 2006-2007, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?, 34 *Syracuse J. Int'l L. & Com.* 429, pp.450-456; All relevant preparatory work documents of the Convention on the Rights of Persons with Disabilities are available at: <http://www.un.org/esa/socdev/enable/disparl.htm#ahcreport>.

⁹⁶ Minkowitz, Tina, 2007, The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions, 34(2) *Syracuse Journal of International Law and Commerce*, p.411.

⁹⁷ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.12.

“respect” which requires basically only a negative obligation from States.⁹⁸ Therefore, it can be argued that using the term “recognize” in Article 12(2) indicates that States parties are obligated to promote, protect and fulfil the right to legal capacity on an equal basis with others in all areas of life. The phrase “in all areas of life” in this second paragraph refers to the fact that this right is not restricted to any specific spheres and, thus, must be implemented accordingly.⁹⁹ As Oliwer Lewis notes, paragraph two does not allow any exceptions and, therefore, States parties are required to protect and promote the right to legal capacity on an equal basis regardless of available resources or the severity of the individual’s impairment.¹⁰⁰

The CRPD Committee highlights that mental capacity and legal capacity must be perceived as two distinct concepts. Mental capacity concerns the decision-making skills a person has which are different in every one of us and can change due to, e.g., environmental factors.¹⁰¹ Legal capacity refers to the legal standing (ability to hold rights and duties) and legal agency (ability to exercise rights and duties) of a person. Previous legal instruments before the CRPD have not elaborated on the difference between these two concepts. Under Article 12(2) of the CRPD the deprivation of legal capacity cannot be legitimately grounded on deficits in an individual’s mental capacity. Instead, Article 12(3) requires that States parties provide support in the exercise of legal capacity in such situations.¹⁰²

Paragraph three of Article 12 of the CRPD regulates the state obligation, which is a necessary prerequisite for the realization of the right to legal capacity on an equal basis with others. Paragraph three states that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” According to the CRPD Committee this means that States parties are required to abstain from deprivations of legal capacity and provide necessary support that persons with disabilities might need to be able to decide themselves on matters that have

⁹⁸ Quinn, Gerard & Alston, Philip, 1987, The nature and Scope of States Parties’ obligations under the International Covenant on Economic, Social and Cultural Rights, 9(2), *Human Rights Quarterly*, p.156.

⁹⁹ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.85-86.

¹⁰⁰ Lewis, Oliver, 2011, Advancing Legal Capacity Jurisprudence, 6 *European Human Rights Law Review*, 700, p.704.

¹⁰¹ The CRPD Committee underlines that the concept of mental capacity is contentious and not in the least objective (para.14).

¹⁰² UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.13 and 15.

legal effects.¹⁰³ However, even day-to-day decisions may require exercising legal capacity for persons who live in institutions, group homes and other similar settings. These decisions might include, e.g., the control of finances and daily schedule. If the person does not actively seek control, the decisions are taken by the institutional authority. Unfortunately, in many cases even if the person intends to express her will to the institutional authority, it is not taken into account.¹⁰⁴

If we examine Article 4 of the CRPD in relation to Article 12(3) we can note that the phrase “take appropriate measures” in Article 12(3) refers to the obligations in Article 4. Article 4 establishes the general obligations that States parties are required to undertake in order to realize all the rights enumerated in the Convention. Clause 1b of the first paragraph of Article 4 particularly regulates that States parties are required to undertake “all *appropriate measures*, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.”¹⁰⁵ When examining Article 12(3) and 4 of the CRPD together we can come to a conclusion that “appropriate measures” in Article 12(3) contain a wide range of action which form a non-exhaustive list. Legislative and administrative measures are examples of different ways to fulfil this obligation.¹⁰⁶

Article 12(3) of the CRPD does not regulate about what establishes “support” for the exercise of legal capacity. Before the CRPD Committee issued its General Comment on Article 12, States parties were uncertain how to start implementing the support paradigm in their jurisdictions. It appears that the drafters of the CRPD have given States parties the freedom to create the kind of structure and nature of support that best suits their jurisdiction. In any case, the provided support must fulfil the obligations enumerated in Article 12.¹⁰⁷ The state obligation to provide support in exercising legal capacity can be regarded as *a right* to receive support in exercising one’s legal capacity. This perspective highlights the status of persons with disabilities as subjects and not

¹⁰³ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.16.

¹⁰⁴ See Arstein-Kerslake, Anna & Flynn, Eilíonóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), pp.10-11.

¹⁰⁵ Article 4(1b), CRPD (emphasis added).

¹⁰⁶ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.86.

¹⁰⁷ See Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.86.

objects.¹⁰⁸ Professor Quinn argues that paragraph three of Article 12 of the CRPD influences deeper than solely the decision-making, as the meaning behind providing supports is to “work to retrieve the will – no matter how hidden – or to create conditions of social embeddedness to spark the will”¹⁰⁹ of the person concerned. It is also important to acknowledge that not all persons with disabilities wish to receive support in exercising their legal capacity as the mere recognition of having the right to legal capacity can be sufficient.¹¹⁰

Paragraph four of Article 12 of the CRPD regulates about the different safeguards that must be established by the States parties in their jurisdiction. The paragraph states that “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.”

Article 12(4), is probably the most contentious of all the provisions in Article 12. It can be interpreted to tacitly legitimize guardianship arrangements alongside with supported decision-making.¹¹¹ On the other hand, proponents of the new paradigm shift argue that Article 12(4) applies solely to supported decision-making.¹¹² Legal scholars are more and more advocating for the replacement of substituted decision-making with the support paradigm¹¹³ and the CRPD Committee has confirmed this approach in its concluding

¹⁰⁸ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.86; See also Vivanti, Donata, (2015), Persons with Disabilities and the Right to Equality Before the Law: Contribution from the European Disability Forum, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.153.

¹⁰⁹ Quinn, Gerard, Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD, Concept Paper, HPOD Conference, Harvard Law School, 20 February, 2010, p.13.

¹¹⁰ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.19.

¹¹¹ See Dhanda, Amita, 2006-2007, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future, 34 *Syracuse Journal of International Law and Commerce* 429.

¹¹² Arstein-Kerslake, Anna, 2015, A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.85-87.

¹¹³ See, e.g. Quinn, Gerard & Arstein-Kerslake, Anna, 2012, Restoring the “human” in “human rights”, in Gearty, C. & Douzinas, C. (Eds.), *Cambridge Companion to Human Rights Law*, Cambridge: Cambridge

observations over the years as well as in the recent General Comment on Article 12.¹¹⁴ Using the verb “ensure” in this provision implies a strong positive obligation on the States parties to realize this right.¹¹⁵ The CRPD Committee defines the term “undue influence” in its General Comment as “occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation.”¹¹⁶

Safeguards envisioned in Article 12(4) of the CRPD must protect against such influence while respecting the rights, will and preferences of persons with disabilities. Although these safeguards must protect individuals from abuse, the protection must be provided on the same grounds as to persons without disabilities. Moreover, the CRPD Committee specifically states that in situations where a person’s will and preferences are not to be found, the paradigm of “best interpretation of will and preferences” should be used instead of relying on determinations of “best interests” of the person. However, the “best interest” principle should continue to be applied in relation to children.¹¹⁷

The question of persons with disabilities who cannot make decisions even with support was raised during the negotiations of the treaty. According to this view, in these cases substituted decision-making should be allowed and safeguards put in place to give protection against abuse.¹¹⁸ The General Comment of the CRPD Committee states that the paradigm of “best interpretation of will and preferences” should be used in these situations.¹¹⁹ The standard of “best interests” is criticized in this modern legal capacity approach, because it enables the substitute decision-maker to decide on the basis of what

University Press; McSherry, Bernadette, 2012, Legal Capacity under the Convention on the Rights of Persons with Disabilities, 2012, 20 *Journal of Law and Medicine* 22, Piers Gooding, ‘Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law’ (2012) *Psychiatry, Psychology and Law* 1; Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario; Tornberg, Johanna, Edunvalvontaoikeus, in Kuuliala, Matti & Tornberg, Johanna (Eds.), Suomen edunvalvontaoikeus, Helsinki: Talentum, p.10.

¹¹⁴ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.3, 23, 26 and 28; See also e.g. Concluding Observations of the Committee on the Rights of Persons with Disabilities: Peru, 7th sess, UN Doc CRPD/C/PER/CO/1 (16 May 2012), para.22-27.

¹¹⁵ See Quinn, Gerard & Alston, Philip, 1987, The nature and Scope of States Parties’ obligations under the International Covenant on Economic, Social and Cultural Rights, 9(2), *Human Rights Quarterly*, p.156.

¹¹⁶ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.22.

¹¹⁷ Ibid., at para.20-22 and 36.

¹¹⁸ Dhanda, Amita, 2006–2007, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?, 34 *Syracuse Journal of International Law and Commerce*, p.445.

¹¹⁹ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1.

she or he considers to be in the best interests of the person. The will or preference of the person may not be taken into account.¹²⁰

When examining this debate in the light of the human rights of persons with disabilities, the provisions of treaty interpretation in international law must be applied. According to the Vienna Convention, articles of a treaty must be interpreted taking into account the text as a whole.¹²¹ As we have explored previously in this paper, the CRPD can be seen to embody a paradigm shift that places persons with disabilities as subjects of their own life instead of living as passive objects. The Convention endeavors to ensure the “equal enjoyment of all human rights and fundamental freedoms” as well as to promote “inherent dignity” of persons with disabilities.¹²²

The preamble of the CRPD, especially sections *n* and *j* highlight the importance of autonomy and the need to protect human rights of also persons with “intensive” support needs.¹²³ Article 3 of the CRPD enumerates general principles of the Convention that apply to all of its articles. These include, for example, the obligation to respect individual autonomy and independence of persons with disabilities. The principle of respecting individual autonomy specifically refers to the right to make one’s own decisions. In addition to the above elaborations, Article 12 should be examined together with especially Article 19 (the right to live independently and to be included in the community).¹²⁴ When Article 19 of the CRPD is taken into account together with Article 12(3) of the CRPD, the strongest argument seems to be the use of community-based approach when providing support to exercise legal capacity. Communities should be regarded as “partners” in the journey of learning what works and what does not work with different types of supports. Moreover, States parties should acknowledge the already existing social networks in their communities as well as the support that naturally emerges within the society, such as support from a person’s family and friends. The overall goal of the CRPD is to enhance the full inclusion of persons with disabilities into their communities.¹²⁵

In the light of these observations, it becomes clear that the CRPD as a whole endorses supported decision-making. Yet, as professor Dhanda notes, the text of Article 12 does not

¹²⁰ Dhanda supra note 118, at p.441.

¹²¹ Article 31, Vienna Convention on the Law of Treaties.

¹²² Article 1, CRPD.

¹²³ Preamble (j), CRPD.

¹²⁴ See Dhanda supra note 118, at p.457.

¹²⁵ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.45.

straightforwardly prohibit substituted decision-making.¹²⁶ The provisions of Article 12 remain silent on this issue due to the disagreements between negotiators in the drafting process of the treaty.¹²⁷ However, Dhanda argues that an interpretation of Article 12 that would “justify” substituted decision-making can only be formulated if Article 12 is read in a vacuum without considering the paradigm shift and the concept of universal legal capacity that Article 12 is promoting.¹²⁸ Furthermore, various other articles of the CRPD require full legal capacity for their realization.¹²⁹

Some States, such as Canada, have made a reservation relating to Article 12 in which they declare their right to continue using substituted decision-making.¹³⁰ Many States, Finland included, reacted after the draft General Comment of the CRPD on Article 12, because it expressly called for the abolishment of substituted decision-making systems.¹³¹ The Finnish Human Rights Center stated in its submission to the Committee that substituted decision-making should be allowed in cases where support is not sufficient.¹³²

All in all, it appears that the debate is not questioning the paradigm shift of legal capacity, but mainly the prohibition of using substituted decision-making as a last resort. The fact that there are individuals in the world whose will and preferences cannot be found even with support, should not be ignored.¹³³ The CRPD Committee has answered to these concerns by advising States parties to rely on the “best *interpretation*” of the person’s will and preferences. Although, the decision is taken on behalf of the person, the approach is completely different as the person’s will is at the center of the decision-making instead of her objective “best interests”. This is the approach that respects a person’s right to self-determination and dignity.

¹²⁶ Dhanda, Amita, 2006-2007, Legal Capacity in the Disability Rights Convention: *Stranglehold of the Past or Lodestar for the Future?*, 34 Syracuse J. Int’l L. & Com. 429, pp. 460-461.

¹²⁷ Ibid., at pp.438-456; see also Salzman, Leslie, 2011, Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative?, 4 *St. Louis U. J. Health L. & Pol’y* 279, p.284.

¹²⁸ Dhanda, Amita, 2006-2007, Legal Capacity in the Disability Rights Convention: *Stranglehold of the Past or Lodestar for the Future?*, 34 Syracuse J. Int’l L. & Com. 429, pp. 460-461.

¹²⁹ Ibid., at pp. 460-461.

¹³⁰ All reservations and declarations to Article 12 of the CRPD are available at: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtsg_no=IV-15&chapter=4&lang=en. Accessed 21.3.2016.

¹³¹ For a list of all the submissions on the draft General Comment of the CRPD Committee, see <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>. Accessed 21.3.2016.

¹³² Submission by the Finnish National Human Rights Center (NHRI) on Article 12, available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>.

¹³³ Dhanda, Amita, 2006-2007, Legal Capacity in the Disability Rights Convention: *Stranglehold of the Past or Lodestar for the Future?*, 34 Syracuse J. Int’l L. & Com. 429, pp.438-456.

Paragraph 5 of Article 12 of the CRPD can be seen to further advance the argument that Article 12, when looked at as a whole, does not allow regimes of guardianship and other substituted decision-making.¹³⁴ Paragraph 5 provides that “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.”¹³⁵ The requirement to “take all appropriate and effective measures” refers to the general obligations of States parties that are enumerated in Article 4 of the CRPD. It is noteworthy that paragraph 5 of Article 12 uses the verb “ensure” that implies a strong positive obligation.¹³⁶ In many countries controlling finances of individuals who are perceived as unable to manage it on their own, is the main reason for the use of guardianship regimes.¹³⁷

There appears to be a firm link between paragraph five and paragraph two of Article 12 of the CRPD. If a person is granted legal capacity on an equal basis with others as regulated in paragraph two, the rights guaranteed in paragraph 5 would also be covered. The reason for having these two separate provisions in Article 12 is most likely to highlight that the right to legal capacity includes both the capacity to be a holder of rights as well as the capacity to act under the law. Paragraph 5 can be understood as not regulating any new rights in addition to the other paragraphs in Article 12.¹³⁸

Legal capacity can be restricted under Article 12 on the same grounds it can be restricted for people without disabilities. Therefore, it can still be restricted due to a commitment of a crime or bankruptcy. Article 12 mainly underlines the obligation of States parties to provide support in the exercise of legal capacity instead of setting up functional tests to assess mental capacity as a threshold to making legally recognized decisions.¹³⁹ Professor Dhanda phrases the issue around the two different paradigms as follows:

¹³⁴ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, p.87-88.

¹³⁵ Article 12(5), CRPD.

¹³⁶ Arstein-Kerslake, Anna, supra note 134, at p.87-88.

¹³⁷ Lewis, Oliver, 2011, Advancing Legal Capacity Jurisprudence, 6 *European Human Rights Law Review* 700, p.705.

¹³⁸ Ibid., at pp.87-88; UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.23.

¹³⁹ Flynn, Eilíonóir & Arstein-Kerslake, Anna, 2014, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity', *International Journal of Law in Context*, 10(1), p.88.

“Fundamentally, there are two choices before humankind. One recognizes that all persons have legal capacity and the other contends that legal capacity is not a universal human attribute.”¹⁴⁰ The acknowledgement of universal legal capacity perceives that every human being can develop if they are given a chance.¹⁴¹

2.4.1 State obligations under Article 12

There are differing views among commentators about the nature of the obligations in Article 12 of the CRPD. Some legal scholars, such as Kerzner, consider that Article 12 can be seen to include both civil and political rights as well as economic, social and cultural rights. According to this view the paragraph three of Article 12, which concerns the obligation to provide support in the exercise of legal capacity, would constitute an economic, social and cultural right, whereas Articles 12(1) and 12(2) would be civil and political rights.¹⁴² The CRPD Committee states clearly in its General Comment that the right to equal recognition before the law is a civil and political right. Furthermore, the Committee specifically highlights that the obligation of Article 12(3) is an obligation that is required for the fulfillment of the right to equal recognition before the law. Consequently, progressive realization does not apply to it.¹⁴³ In international law, civil and political rights require immediate realization from the States parties, and such rights apply to individuals at the moment of ratification. If Article 12 is considered as a civil and political right, then progressive realization would not be sufficient and the rights guaranteed in Article 12 would apply to persons with disabilities at the moment of ratification.¹⁴⁴

The CRPD Committee elaborates with great detail in the General Comment about the obligations Article 12 sets out to States parties. One practical instruction is that States parties “must review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported

¹⁴⁰ Dhanda, Amita, 2006-2007, Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?, 34 Syracuse J. Int'l L. & Com. 429, p.457.

¹⁴¹ Ibid., at pp. 456-458.

¹⁴² Kerzner, Lana, 2011, Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: a Canadian perspective. Prepared for In From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century. University of British Columbia, Canada April 2011, p.25.

¹⁴³ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.1 and 30.

¹⁴⁴ Ibid., at para.30.

decision-making, which respects the person's autonomy, will and preferences".¹⁴⁵ The Committee states that the requirements of Article 12 of the CRPD are not fulfilled if regimes of substituted decision-making continue to exist in parallel with systems of supported decision-making.¹⁴⁶ This is a progressive interpretation of Article 12 as it does not allow a transition time where substituted decision-making would be maintained in some form. Interestingly, States which have started to implement Article 12 of the CRPD, have chosen to maintain their regimes of substituted decision-making while providing new options of support in the exercise of legal capacity. Two examples are the Province of British Columbia in Canada and Sweden.¹⁴⁷

In the light of human rights of persons with disabilities, the interpretation of the CRPD Committee is strongly supported as long as the transition to the new paradigm of supported decision-making is performed properly with effective safeguards. Nevertheless, even from this human rights perspective the system of supported decision-making is not without concerns that need to be taken seriously. These concerns and criticisms are assessed in the next chapter. It is important for the States parties to recognize that Article 12 requires more than just reforming regimes of substituted decision-making. Article 12(2) of the CRPD regulates that persons with disabilities must enjoy legal capacity on an equal basis with others "in all aspects of life".¹⁴⁸ The fulfilment of this obligation requires reform of various branches of domestic law in States parties, such as in contract law, criminal law and laws related to health care.¹⁴⁹

2.4.2 Relationship of Article 12 with the other CRPD articles

The right to equal recognition before the law of Article 12 has a great impact on the other articles in the CRPD, such as to the right to access justice (art. 13); the right to liberty and security of the person (art. 14); the right to respect for one's physical and mental integrity (art. 17); the right to liberty of movement and nationality (art. 18); the right to choose where one wants to live and with whom (art. 19); the right to freedom of expression and opinion (art. 21); the right to marry and found a family (art. 23); the right to consent to medical treatment (art. 25); and the right to participate in political and public life (art.

¹⁴⁵ Ibid., at para.26.

¹⁴⁶ Ibid, at para.28.

¹⁴⁷ See Arstein-Kerslake, Anna & Flynn, Eilíonóir, 2015, The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.8.

¹⁴⁸ Article 12(2), CRPD.

¹⁴⁹ Arstein-Kerslake & Flynn supra note 147, at p.11.

29).¹⁵⁰ The relationship of Article 12 in relation to Articles 5 and 9 of the CRPD are further examined in this subsection.

Equal recognition before the law cannot be realized if legal capacity is deprived in a discriminatory manner of people with disabilities. Equality is at the core of the CRPD and it is mentioned in Articles 1-5 of the CRPD as well as in the preamble.¹⁵¹ International human rights law has shifted from formal equality to substantive equality that recognizes positive measures as mandatory tools in obtaining equality in situations of factual inequality.¹⁵² Substantive equality not only recognizes human diversity, but “expects difference”.¹⁵³ Article 5 of the CRPD is the main article for the protection of equality in the CRPD. The definition of discrimination on the basis of disability is regulated in Article 2 of the CRPD stating that such discrimination refers to “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation”.¹⁵⁴

Consequently, deprivation of legal capacity which results to discrimination either in purpose or in effect violates articles 12 and 5 of the CRPD. Denials of legal capacity must be realized on the same grounds for everyone.¹⁵⁵ This is critical for States parties under processes of legal capacity reforms as establishing regimes that appear to be non-discriminatory on the basis of disability, but have discriminative effect (even unintended) against persons with disabilities, are considered violating Article 5 of the CRPD.¹⁵⁶

¹⁵⁰ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.31.

¹⁵¹ Arstein-Kerslake, Anna, (2015), A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, Vol.5, p. 81-82.

¹⁵² Kumpuvuori, J., & Scheinin, M., 2009, Treating the Different Ones Differently – a Vehicle for Equality for Persons with Disabilities? Implications of Article 5 of the Convention on the Rights of Persons with Disabilities, in Kumpuvuori, J., & Scheinin, M. (Eds.), *United Nations Convention on the Rights of Persons with Disabilities – Multidisciplinary Perspectives*, Helsinki: The Center for Human Rights of Persons with Disabilities in Finland (VIKE), pp.62, 56, 65-66.

¹⁵³ Kayess, R. & French, P., Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities, *Human Rights Law Review*. 8:1, Oxford University Press. 2008, p.11.

¹⁵⁴ Article 2, CRPD.

¹⁵⁵ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.32.

¹⁵⁶ Arstein-Kerslake, Anna, 2015, A call to Action: The realization of equal recognition under the law for people with disabilities in the EU, In Waddington L., Quinn G. (Eds.), *European Yearbook of Disability Law*, Vol.5, p. 81-82.

People with physical disabilities are accommodated with a ramp to access a building, and the same idea is behind accommodating people with cognitive disabilities with supported decision-making to exercise their legal capacity.¹⁵⁷ It is noteworthy that denial of reasonable accommodation can form discrimination on the basis of disability as the right to equality contains the right to reasonable accommodation in the exercise of legal capacity.¹⁵⁸ Therefore, if a legal order, e.g., fails to recognize different forms of communication or, in general, fails to provide the necessary support for the exercise of legal capacity, it may be regarded both as discrimination on the basis of disability (Article 5 of the CRPD) as well as violating the right to equal recognition of legal capacity (Article 12 of the CRPD).¹⁵⁹ The relationship between reasonable accommodation of Article 5(3) and the support to the exercise legal capacity of Article 12(3) will be further examined in the next chapter.

The right to equal recognition before the law is closely connected with the right to accessibility in Article 9 of the CRPD. Inaccessible information and communication, as well as inaccessible services can form barriers that prevent some persons with disabilities to exercise their right to legal capacity. When looking at Article 9 together with Article 12 of the CRPD, States parties are obligated to make sure that all procedures, information and communication related to the exercise of legal capacity are completely accessible for persons with disabilities.¹⁶⁰

¹⁵⁷ Salzman, Leslie, 2010, Rethinking guardianship (again): substituted decision making as a violation of the integration mandate of title II of the Americans with Disabilities Act, *Cardozo Legal Studies Research Paper No 282*, University of Colorado Law Review, 81, pp.157–245.

¹⁵⁸ Articles 2, 5(3) and 12, CRPD.

¹⁵⁹ Arstein-Kerslake, Anna & Flynn, Eilíonóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.11.

¹⁶⁰ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.37.

3. A system of supported decision-making

3.1 The nature of supported decision-making

Supported decision making was created in Canada. The Canadian Association for Community Living Taskforce wrote the first principles of supported decision-making in their report on Alternatives to Guardianship in 1992.¹⁶¹ International attention was directed at supported decision-making during the negotiations of Article 12 of the CRPD, where it was introduced as the legal framework that could fulfil the obligation to provide support in the exercise of legal capacity.¹⁶² As a result of the CRPD, supported decision-making now has a basis in international human rights law.¹⁶³

The term “supported decision-making” appears in several different contexts and there are various models that claim to belong to its realm, which can make it difficult to perceive what kind of a system it is.¹⁶⁴ Some commentators have stated that supported decision-making is, in fact, an “ill-defined concept”.¹⁶⁵ The confusion is partly due to the fact that supported decision-making is connected with several different dimensions, such as: legal measures and informal measures; state action and measures of civil society; as well as different degrees and types of support.¹⁶⁶ There are differing views in the literature about whether the concept of supported decision-making should only concern legal measures or if it should also include informal arrangements without legal enforceability.¹⁶⁷

Supported decision-making is often portrait as an opposite of substituted decision-making, such as adult guardianship, which does not respect person’s autonomy and dignity to the

¹⁶¹ Browning, M., Bigby, C., & Douglas, J., 2014, Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice, *Research & Practice in Intellectual & Developmental Disabilities*, 1(1), p.35.

¹⁶² Ibid., at pp.35-36.

¹⁶³ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity, *International Journal of Law in Context* 10 (1), p.88.

¹⁶⁴ Ibid., at p.36; See also Salzman, Leslie, 2011, Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative?, 4 *St. Louis U. J. Health L. & Pol’y* 279, pp.306-307; Carney, Terry, 2014, Clarifying, Operationalising, and Evaluating Supported Decision Making Models, *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), p.46; Then, Shih-Ning, 2013, Evolution and innovation in guardianship laws: Assisted decision-making, *Sydney Law Review*, 35(1), 133–166.

¹⁶⁵ Carney supra note 164, at pp.42-43.

¹⁶⁶ Carney, Terry & Beaupert, Fleur, 2013, Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making, 36 *University of New South Wales Law Journal* 175, pp.180-181.

¹⁶⁷ Gooding, Piers, 2015, Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review* (accepted for publication), pp.9-10; see also Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, pp.1121, 1123-1124.

same extent.¹⁶⁸ The CRPD Committee has defined substituted decision-making 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, as opposed to being based on the person’s own will and preferences.”¹⁶⁹

To begin with, it is important to separate two concepts from each other: “support to exercise legal capacity” and “supported decision-making”. Neither Article 12(3) of the CRPD nor the Convention as a whole further elaborate about the “support to exercise legal capacity”. The CRPD Committee has given its own definition in the General Comment on Article 12 where the Committee states that “support is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity.”¹⁷⁰ Therefore, supported decision making is one *type* of support among others to exercise legal capacity.¹⁷¹

Systems of supported decision-making can take various different forms.¹⁷² It is important to take into account the specific cultural and political framework of the State party in question.¹⁷³ Based on the definition of the CRPD Committee, a regime of supported decision-making contains several different options to support persons with disabilities in the exercise of legal capacity. Supported decision-making respects person’s will and preferences while following and protecting all the human rights norms – both rights related to autonomy as well as rights related to freedom from abuse and exploitation. The Committee has made a list of provisions which all the different forms of systems of supported decision-making should incorporate in order to fulfil the requirements of Article

¹⁶⁸ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity, *International Journal of Law in Context* 10 (1), p.84; See also Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, p.1142.

¹⁶⁹ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.27.

¹⁷⁰ *Ibid.*, at para.17.

¹⁷¹ Gooding, Piers, 2015, Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review* (accepted for publication), p.11 (emphasis added).

¹⁷² Arstein-Kerslake, Anna & Flynn, Eilionóir, 2014, The Support Model of Legal Capacity: Fact, Fiction or Fantasy?, 32(1) *Berkeley Journal of International Law*, p.132.

¹⁷³ *Ibid.*, at p.132.

12(3) of the CRPD.¹⁷⁴ First of all, regimes of supported decision-making must be made available to everyone regardless of the severity of impairment and level of support needs. The support given in the system of supported decision-making must be based on the will and preference of the person, instead of relying on the principle of “best interests”. Different ways of communication must be accommodated and must never become a barrier to receiving support in decision-making. A system of supported decision-making must provide accessible legal recognition of the support person who is formally chosen by the person herself/himself. Related to this obligation States are required to facilitate the establishment of support especially towards individuals who are isolated from the community and provide a mechanism that would verify the identity of a support person in relation to third parties.¹⁷⁵

In addition to these provisions, the CRPD Committee clarifies that the term “to provide access” as used in paragraph three of Article 12, signifies that States parties must guarantee support which is available for free or for a minimal cost to persons with disabilities. The need for support in decision-making must never be considered as a justification for restricting other fundamental right of persons with disabilities, such as parental rights. A very important aspect is that support is never imposed on a person and the person has the right to change the support relationship as well as to terminate it whenever she or he so desires. States parties must establish safeguards that cover all the processes concerning the support to exercise legal capacity in order to guarantee that the person’s will and preferences are respected. Lastly, but most importantly, States parties are required to create new indicators of support needs that are non-discriminatory in order to prevent excluding people from the scope of support. Assessments of mental capacity are no longer acceptable under Article 12 of the CRPD.¹⁷⁶

Formalized supported decision-making can be realized, for example, with a legally enforceable agreement between a person with disabilities and a third party. These agreements may concern pre-existing supported decision-making relationships, which the State then legally recognizes, or they may relate to relationships that are created in order to provide “state-sanctioned support”.¹⁷⁷ Perhaps the most common example of a

¹⁷⁴ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.29.

¹⁷⁵ Ibid., at para.29.

¹⁷⁶ Ibid., at para.29.

¹⁷⁷ Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, pp.1121, 1123-1124.

formalized supported decision-making model is the Representation Agreement of the Province of British Columbia in Canada.¹⁷⁸ Regardless of the fact that supported decision-making is often described as involving only a single support person, private supported decision-making can also be realized by using a “circle of support” or a “microboard”. In terms of public appointments, supported decision-making is organized by a municipal government in Sweden.¹⁷⁹

Arstein-Kerslake and Flynn argue that it is probable that the best system of supported decision-making adopts both formal and informal forms of support. However, they note that both of these approaches have their concerns, as informal support may lack sufficient safeguards and formal support may turn into another barrier to overcome before the individual can have her decision recognized.¹⁸⁰ Carney points out that the boundary line between public and private law in relation to the provided support is unclear. He states that non-statutory written support agreements evidently form part of private law and, therefore, may involve contractual and fiduciary duties. On the other hand, support agreements which are provided by a statute, could involve either obligations under private law or “confer statutory public powers on supporters governed by administrative law” – or even both of these.¹⁸¹ Carney therefore recommends that policy makers carefully ponder on the effect of these different options.¹⁸² Moreover, the issue of representative’s liability under supported decision-making must be determined in legislation.¹⁸³

Personal support networks are crucial factors for the successful operation of supported decision-making. However, Stainton notes that most jurisdictions do not focus on their development and maintenance. The creation of a legal framework that is compatible with Article 12 of the CRPD is not enough on its own. The effective practice requires structural and social supports; mechanisms that help building support networks for persons who do

¹⁷⁸ Ibid., at pp.1121, 1123-1124.

¹⁷⁹ Ibid., at pp.1121, 1123-1124.

¹⁸⁰ Arstein-Kerslake, Anna & Flynn, Eilíonóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.6.

¹⁸¹ Carney, Terry & Beaupert, Fleur, 2013, Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making, 36 *University of New South Wales Law Journal* 175, pp.187-188.

¹⁸² Ibid., at pp. 187-188.

¹⁸³ For a further discussion, see Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 *Sydney Law Review*, pp.158-159.

not have access to them, and mechanisms that help sustaining these networks once they are established.¹⁸⁴

Browning, Bigby and Douglas remind practitioners that the aim of supported decision-making is not solely to provide support with decision-making, but to support persons to exercise their legal capacity. Supported decision-making is, thus, more broadly about creating alternative legal mechanisms, such as Representation Agreements and Microboards.¹⁸⁵ Supported decision-making can be seen both as a process led by the person, as well as an end, which legally recognizes the support that is provided in decision-making and gives legal standing to decisions that are made through such a process.¹⁸⁶ In this sense, supported decision-making can be seen as a regime that intends to replace guardianship arrangements.¹⁸⁷

Supported decision-making as a process can be summarized to occur when a person with cognitive impairments receives support from one or more supporters who explain matters to her and, if necessary, interpret her will and preferences from her words and actions. Above all, the person herself or himself is the primary decision-maker.¹⁸⁸ In other words, the question is no longer whether a person has legal capacity or not, but what supports could be provided for the person to enable her or him to exercise legal capacity.¹⁸⁹ Salzman has listed common characteristics of different models of supported decision-making which scholars have agreed upon: (i) the individual is the primary decision-maker; (ii) the support is based on the person's consent and never imposed on her; (iii) the person

¹⁸⁴ Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, Research and Practice in Intellectual and Developmental Disabilities, published online 15 Oct 2015, p.6.

¹⁸⁵ Ibid., at pp.39, 41-42.

¹⁸⁶ See Browning, M., Bigby, C., & Douglas, J., 2014, Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice, *Research & Practice in Intellectual & Developmental Disabilities*, 1(1), p.37; ¹⁸⁶ Quinn, Gerard, 2010, Personhood and Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD, HPOD Conference Harvard Law School 20 February 2010; Kerzner, Lana, 2011, Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: a Canadian perspective. Prepared for In From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century. University of British Columbia, Canada April 2011.

¹⁸⁷ Dinerstein, Robert, 2012, Implementing legal capacity under article 12 of the UN convention on the rights of persons with disabilities: the difficult road from guardianship to supported decision-making, *Human Rights Brief*, 19(2), pp.8-12.

¹⁸⁸ See United Nations Enable, 2007, Handbook for Parliamentarians on the Convention of Rights of Persons with Disabilities, chapter 6; Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario, pp.167-169.

¹⁸⁹ See generally Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario; Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity, *International Journal of Law in Context* 10 (1), p.90.

is an active participator in the decision-making process; and (iv) decisions that are reached through supported decision-making are usually legally enforceable.¹⁹⁰

Finally, the notion of “dignity of risk” is very relevant to the support paradigm. Every human being has the right to make bad and risky decisions after having been given the necessary information and support for the decision-making, as well as safeguards to protect the individual from abuse.¹⁹¹ It is worth reiterating that these safeguards must respect the person’s “rights, will and preferences”.¹⁹² A system of support to exercise legal capacity should grant the dignity of risk to everyone and restrain the right to make choices on the same grounds for persons with disabilities as for people without disabilities.¹⁹³ The current reality is, however, that persons with decision-making impairments are denied of the right to make “bad” decisions.¹⁹⁴

3.2 A support model by Arstein-Kerslake and Flynn

The model of Arstein-Kerslake and Flynn was chosen for further examination, because it was introduced by the Vice Chair of the CRPD Committee, Theresia Degener, to the members of the working group preparing the General Comment of the CRPD Committee. Both Arstein-Kerslake and Flynn were invited to support the working group on Article 12 of the CRPD.¹⁹⁵ The model of support created by Arstein-Kerslake and Flynn differs from the models that have been conceptualized before, and it is built on the model of Michael Bach and Lana Kerzner.¹⁹⁶ The characteristic aspect of the model of Arstein-Kerslake and Flynn is that it aims to eliminate completely mental capacity assessments as a means of evaluating the person’s decision-making status. Arstein-Kerslake and Flynn emphasize that their model of support has an inclusive approach that endeavors to benefit the whole

¹⁹⁰ Salzman, Leslie, 2011, Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative?, 4 *St. Louis U. J. Health L. & Pol’y* 279, pp.306-307.

¹⁹¹ Arstein-Kerslake, Anna & Flynn, Eilíonóir, 2014, The Support Model of Legal Capacity: Fact, Fiction or Fantasy?, 32(1) *Berkeley Journal of International Law*, p.142.

¹⁹² UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.20.

¹⁹³ Bach, Michael & Kerzner, Lana, A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, Report to the Law Commission of Ontario 2010, p.184.

¹⁹⁴ Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 *Sydney Law Review*, pp.155-156.

¹⁹⁵ Arstein-Kerslake, Anna & Flynn, Eilíonóir, 2015, The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.2.

¹⁹⁶ See Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario.

society.¹⁹⁷ The biggest differences between the support model of Bach and Kerzner and the support model of Arstein-Kerslake and Flynn, are that the latter model does not accept any functional assessments of decision-making capability and it perceives that persons should be allowed to decide themselves the level of support they need.¹⁹⁸

3.2.1 Wong's potentiality view

Arstein-Kerslake and Flynn frame their support model within the social contract by using the notion of “enabling conditions” from Wong’s potentiality view of Rawls’s Theory of Justice.¹⁹⁹ They argue that, based on Wong’s potentiality view, persons with severe and complex disabilities can be included in Rawls’s conception of the participating citizens²⁰⁰ and, thus, also in the scope of moral personhood.²⁰¹ According to Wong, everyone should be provided with support to develop the “two moral powers” of the participating citizens in Rawls’s theory.²⁰² This can be realized with the help of “enabling conditions”, such as building relationships, becoming part of social groups and taking time to develop one’s capabilities, which enable the individual to develop these moral powers, as well as to express her will and preferences.²⁰³

The primary idea behind Wong’s potentiality view is that all human beings are capable of such development if they are provided with the right environment – i.e. enabling conditions where these powers are acquired.²⁰⁴ This can appear to be a radical and idealistic approach as there are persons in the world who are unable to express their will and preferences in a manner that could be understood by others. However, as Arstein-Kerslake and Flynn point out, medical science is advancing all the time and making

¹⁹⁷ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, *Legislating Personhood: Realizing the Right to Support in Exercising Legal Capacity*, *International Journal of Law in Context* 10(1), p.82.

¹⁹⁸ *Ibid.*, at p.89.

¹⁹⁹ Wong, Sophia I., 2010, *Duties of Justice to Citizens with Cognitive Disabilities*, in Kittay, E. F. and CarlsonL. (eds), *Cognitive Disability and its Challenge to Moral Philosophy*, Chichester: Wiley- Blackwell Publishers.

²⁰⁰ See Rawls (1999).

²⁰¹ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, *Legislating Personhood: Realizing the Right to Support in Exercising Legal Capacity*, *International Journal of Law in Context* 10 (1), pp.92-94.

²⁰² These two moral powers are the capacity for a sense of justice and the capacity for a conception of the good. See Rawls, John (1999), at p.xii.

²⁰³ Wong, Sophia I., 2010, *Duties of Justice to Citizens with Cognitive Disabilities*, in Kittay, E. F. and CarlsonL. (eds), *Cognitive Disability and its Challenge to Moral Philosophy*, Chichester: Wiley- Blackwell Publishers, p.133.

²⁰⁴ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, *Legislating Personhood: Realizing the Right to Support in Exercising Legal Capacity*, *International Journal of Law in Context* 10 (1), p.93.

wonderful discoveries in the field of decision-making process.²⁰⁵ In cases, where it would be absolutely clear that individuals do not have the potential to develop the two moral powers, the society would have two options from which to choose: to consider that this group of persons are not “worthy of moral consideration” or to endeavor to speak on their behalf by trying to interpret their will and preferences.²⁰⁶ Arstein-Kerslake and Flynn agree with Wong that such persons should be included in the spheres of justice as it is always better to overextend the scope of personhood than to deny it.²⁰⁷ We cannot predict the discoveries that science will make in the future. Moreover, when looking at the history of medicine, we notice how claims of physicians have been disproved by later advancements in science. This should direct us to become more cautious with excluding persons from the realms of moral personhood.²⁰⁸

Wong’s notion of “enabling conditions” is especially relevant in relation to legal capacity and making choices. Arstein-Kerslake and Flynn use this term in their model of support to refer to the “ever-present accommodations” which enable people to develop their autonomy and decision-making skills, and thus, to advance on the continuum of support.²⁰⁹ These accommodations include, for example, the recognition of different forms of communication, reasonable accommodation, accessible information and advocacy support.²¹⁰ States are required to provide a “continuum of support measures” which acknowledges universal legal capacity and legally recognizes decisions which are reached through supported decision-making system.²¹¹

The model of Arstein-Kerslake and Flynn is founded on the following principles: universal approach to legal capacity (i.e. that legal capacity inheres in every human being); the

²⁰⁵ See, e.g. Lehrer, Jonah, 2009, *How We Decide*. New York: Houghton Mifflin Harcourt Publishing Company, where Lehrer illustrates how there is no clear difference between emotion and intellect in our decision-making process.

²⁰⁶ Wong, Sophia I., 2010, Duties of Justice to Citizens with Cognitive Disabilities, in Kittay, E. F. and CarlsonL. (eds), *Cognitive Disability and its Challenge to Moral Philosophy*, Chichester: Wiley- Blackwell Publishers, p.133; Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, *International Journal of Law in Context* 10 (1), p.94.

²⁰⁷ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, *International Journal of Law in Context* 10 (1), p.94; Wong, Sophia I., 2010, Duties of Justice to Citizens with Cognitive Disabilities, in Kittay, E. F. and CarlsonL. (eds), *Cognitive Disability and its Challenge to Moral Philosophy*, Chichester: Wiley- Blackwell Publishers, p.133.

²⁰⁸ See Wong, Sophia I., 2010, Duties of Justice to Citizens with Cognitive Disabilities, in Kittay, E. F. and CarlsonL. (eds), *Cognitive Disability and its Challenge to Moral Philosophy*, Chichester: Wiley- Blackwell Publishers.

²⁰⁹ i.e. to move from more intensive forms of support to another level which is less intensive.

²¹⁰ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, *International Journal of Law in Context* 10 (1), pp.94, 97.

²¹¹ Arstein-Kerslake, Anna, & Flynn, Eilionóir, 2014, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, *International Journal of Law in Context* 10 (1), pp.88-89.

abolition of all assessments of decision-making ability which have the result of denying legal capacity; and the elimination of substitute decision-making which uses the determinations of the person's "best interests" instead of her will and preferences. Their model does not prevent that a representative makes a decision for another person in cases where the person is not able to express her will and preferences in a manner that would be possible to comprehend. Their model requires that these representatives reach such decisions by intending to interpret the will and preferences of the person.²¹²

People may require different levels of support within the paradigm of universal legal capacity. Arstein-Kerslake and Flynn argue that this does not establish different legal statuses. Legal capacity, thus, remains with the person regardless of the support measures she or he is provided with. The supporter is responsible to the supported person. The supporter must provide all relevant information relating to the decision in an accessible way to her. The aim of the support relationship is to help the person to express her will and preferences and not to influence the person's decision-making. Furthermore, support model is never imposed to a person and she can always refuse support. For cases where supporters disagree about the will and preferences of the supported person, Arstein-Kerslake and Flynn recommend States to constitute a "higher decision-making body," which would decide, when necessary, what are the will and preferences of the person concerned.²¹³

3.2.2 The continuum of support

Arstein-Kerslake and Flynn have based their model on the continuum of support to exercise legal capacity that was created by Bach and Kerzner.²¹⁴ This continuum of support consists of three different categories of decision-making: (i) legally independent decision-making; (ii) supported decision-making; and (iii) facilitated decision-making. In Arstein-Kerslake's and Flynn's view, the model of Bach and Kerzner conceptualizes these different levels of support as "statuses", while considering that some movement between the legally independent and supported decision-making can occur. Arstein-Kerslake and Flynn consider in their model that these different "points" on the continuum can be exercised at the same time and a person can move along all the different points, depending on the decision at hand and the enabling conditions provided.

²¹² Ibid., at p.94, 96.

²¹³ Ibid., at p.94, 96.

²¹⁴ Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario.

They further argue that despite the category in which an individual is at on the continuum of support, she must always be provided with the enabling conditions – even if these supports seem not to increase the person’s decision-making capabilities.²¹⁵

Legally Independent Decision-Making is the first point on the continuum of support. In this level, a person can make decisions on her own and the society acknowledges her as a legally independent decision-maker. An individual who is considered to function on this level, may require reasonable accommodation in the decision-making process, such as accessible information and the use of informal support from trusted persons. The second point on the continuum of support is Supported Decision-Making, in which the individual is provided with support in decision-making in the areas she desires. A person can have a circle of support that is formed by trusted individuals who are all selected by the supported person and know her well. Supported decision-making can only be provided to a person with her or his consent and never be imposed against the person’s will. The state’s role in this level of support is to ensure that such support is available to persons with disabilities, support agreements can be formalized and to ensure that the decisions reached through supported decision-making are respected by the society.²¹⁶

The third and last point is Facilitated Decision-Making that is used only as a last resort in situations when a person has no circle of support or any other person who could act as an interpreter of the person’s will and preferences. A facilitated decision-maker is appointed to make decisions on behalf of the person, but this is realized by having the person’s interpreted/imagined will and preferences at the core of the decision-making process. For this reason, facilitated decision-making differs from substitute decision-making, which follows the objective principle of the individual’s “best interests”. Furthermore, the facilitator always aims to develop the person’s autonomy and decision-making skills as far as possible.²¹⁷

Arstein-Kerslake and Flynn highlight that a person cannot be “forced into” a category on the continuum of support.²¹⁸ If a person is able to express her will and preferences,

²¹⁵ See Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario; Arstein-Kerslake, Anna, & Flynn, Eilíonóir, 2014, Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity, *International Journal of Law in Context* 10 (1), pp.95-97.

²¹⁶ Arstein-Kerslake, Anna, & Flynn, Eilíonóir, 2014, Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity, *International Journal of Law in Context* 10 (1), p.95.

²¹⁷ *Ibid.*, at pp.95-96.

²¹⁸ Arstein-Kerslake, Anna, & Flynn, Eilíonóir, 2014, Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity, *International Journal of Law in Context* 10 (1), p.97.

facilitated decision-making will never be imposed on her. This applies also in situations where a person's decisions are considered harmful to the person herself or towards other people. In such cases a supporter has the responsibility to intervene by assisting or safeguarding the person, if failure to act would cause legal liability for criminal or civil negligence. The support model aims to guarantee the same "dignity of risk" to persons with disabilities that we all possess.²¹⁹

3.3 Article 12(3) of the CRPD and reasonable accommodation

It is important to understand the difference between reasonable accommodation (Article 5.3 of the CRPD) and the obligation to provide support in the exercise of legal capacity (Article 12.3 of the CRPD). They both refer to giving support, but supported decision-making and other support provided under Article 12(3) extend wider than just reasonably accommodating decision-making.²²⁰

Reasonable accommodation is defined in Article 2 of 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".²²¹ Reasonable accommodation in decision-making concerns the person with disabilities, third parties and the government. The third party involved is required to reasonably accommodate the person, which in some cases can be realized simply by respecting the supports the person uses in decision-making. In other cases reasonable accommodation might require positive measures from the third party to provide the requested support. According to Article 2 of the CRPD, this duty is not unlimited as third parties are obligated to provide such support only until the point of undue hardship.²²²

Although the duty to provide reasonable accommodation (Article 5.3 of the CRPD) and the governments' duty to provide access to support under Article 12(3) of the CRPD overlap

²¹⁹ Ibid., at p.97.

²²⁰ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.34; Browning, M., Bigby, C., & Douglas, J., 2014, Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice, *Research & Practice in Intellectual & Developmental Disabilities*, 1(1), p.42; Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario, pp.111-112.

²²¹ Article 2, CRPD.

²²² Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario, p.111.

conceptually, they differ in their application as the obligation to provide support in the exercise of legal capacity is not restricted by the limit of undue hardship. The CRPD Committee declares that Article 12(3) contains an “absolute obligation”.²²³ However, Bach and Kerzner consider that this is not an unlimited duty on the State as Article 12(3) uses the term “appropriate measures”.²²⁴

3.4 Best practices in Canada

Regardless of the fact that Canada has retained the right to use substituted decision-making as a last resort, it is frequently used as an example of a country with good practices of supported decision-making.²²⁵ Canada is a federal system and, consequently, its provinces have adopted several different models in terms of legal capacity and decision-making. Although some of these models have moved towards supported decision-making, it is worth highlighting that none of them represent the “pure” type of supported decision-making as conceptualized by the CRPD Committee and various legal scholars.²²⁶ The Province of British Columbia is considered to be the province of Canada which has a system of support that comes closest to supported decision-making.²²⁷ The UN High Commissioner for Human Rights has declared that British Columbia is one of the leaders in guaranteeing supported decision-making in the legal framework and policy.²²⁸ Therefore, the support model in this province will be examined further.

3.4.1 The Representation Agreement Act

The Province of British Columbia has developed two distinct support forms for persons with disabilities, which both contain great potential: the Representation Agreement Act and

²²³ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.34.

²²⁴ Bach & Kerzner supra note 222, at pp.111-112.

²²⁵ Canada ratified the CRPD in 2010 and made a reservation regarding Article 12 to retain the right to use substitute decision-making as a last resort. See reservations and declarations to Article 12: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en; See also Booth Glen, Kristin, 2012, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, *Columbia Human Rights Law Review*, 44, p.140; See also Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, p.1126.

²²⁶ See Gordon, Robert, M., 2000, The Emergence of Assisted (Supported) Decision- Making in the Canadian Law of Adult Guardianship and Substitute Decision- Making, 23 *Int'l J.L. & Psychiatry* 61.

²²⁷ Booth Glen, Kristin, 2012, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, *Columbia Human Rights Law Review*, 44, pp.145-146.

²²⁸ UN Office of the High Commissioner for Human Rights (OHCHR), Foreword, Handbook for parliamentarians on the Convention on the Rights of Persons with disability: from exclusion to equality realizing the rights of persons with disabilities, 2007, HR /PUB/07/6, p.90.

Microboards. The Representation Agreement Act (RAA) ²²⁹ was actually the first Act in the world which provides a statutory base for supported decision-making and an alternative to the legal regime of guardianship.²³⁰ The Representation Agreement Act was inspiration for the subsequent legislative initiatives in Manitoba, the Yukon Territory, and Alberta,²³¹ but the British Columbia Act is still the most comprehensive Act regarding supported decision-making in Canada.²³²

The RAA regulates voluntary Representation Agreements, which allow people with disabilities to authorize one or more personal supporters to help them make specific decisions.²³³ The biggest innovation brought by this Act is the change in the way capacity is understood.²³⁴ The RAA relies on the presumption of capacity and there is only a minimal requirement of capacity to be able to create a standard Representation Agreement.²³⁵ Furthermore, an adult's way of communication cannot affect the presumption of her or his capacity to make a Representation Agreement.²³⁶ The law, therefore, recognizes that some adults do not communicate in a traditional way and may use, for example, only non-verbal gestures and body-language.²³⁷

There are two types of Representation Agreements that can be entered into: the Standard Powers of section 7, and a broader set of powers of section 9 of the Representation Agreement Act. These two types of powers differ greatly regarding determinations of

²²⁹ Representation Agreement Act, R.S.B.C. 1996, c. 405 (Can.).

²³⁰ Gordon, R. M., 2000, The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making, *International Journal of Law and Psychiatry*, 23(1), 61-77.

²³¹ For a more detailed discussion of the Canadian legal framework see Kerzner, Lana, 2011, Paving the way to full realization of the CRPD's rights to legal capacity and supported decision-making: A Canadian perspective. Vancouver: CIC. Retrieved from http://citizenship.sites.olt.ubc.ca/files/2014/07/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf

²³² Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, *Research and Practice in Intellectual and Developmental Disabilities*, p.4.

²³³ Booth Glen, Kristin, 2012, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, *Columbia Human Rights Law Review*, 44, pp.145-146; Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, *Research and Practice in Intellectual and Developmental Disabilities*, pp.4-5.

²³⁴ Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, *Research and Practice in Intellectual and Developmental Disabilities*, pp.4-5.

²³⁵ See Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt. 1.3 and pt.2.8 (Can.). According to the section 1 of the Act, an adult is a person who is 19 years old.

²³⁶ Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt. 1.3 (Can.).

²³⁷ Fact sheet about a Representation Agreement with Section 7 Standard Powers, Nidus personal Planning Resource Center and Registry, March 2012. Available at: http://www.nidus.ca/PDFs/Nidus_FactSheet_RA_Section7.pdf. (last accessed 29.03.2016)

incapability.²³⁸ In relation to the Standard Powers, an adult can make a representation agreement “even though the adult is incapable of: (a) making a contract, or (b) managing his or her health care, personal care, legal matters, or c) the routine management of financial affairs.”²³⁹ Therefore, a person who would be considered incapable to execute an enduring power of attorney, is capable to create a Standard Agreement under section 7 of the RAA.²⁴⁰ On the contrary to the Standard Powers, agreements under section 9 can only be made by an adult who understands “the nature and consequences of the proposed agreement.”²⁴¹ The incapability test required by this section is similar to the traditional “understand information and appreciate consequences” –test.²⁴² Kerzner argues that the agreements entered into under section 9 of the Representation Agreements Act are not support agreements as the representative is authorized to make decisions on behalf of the person and there are no provisions on helping the person with disabilities in decision-making.²⁴³

The Standard Powers of section 7 include the following four areas of authority: (a) routine management of financial affairs; (b) minor and major health care; (c) personal care; and (d) obtaining legal services and instructing a lawyer. Agreements under section 7 do not require legal consultation or, as mentioned above, a specific test of capability. However, they do require a monitor to be named in cases where the Agreement confers authority for the routine management of financial affairs, unless the representative is a spouse or two or more representatives act jointly.²⁴⁴ The monitor must report to the Public Guardian and Trustee if she or he considers that the representative is not complying with the duties of representatives.²⁴⁵ The signing of all Agreements must be witnessed as further regulated in section 13 of the Act.

The section 9 of the RAA sets out a broader set of powers which extend beyond the routine management of a person’s affairs of section 7. Under this section a person can authorize his or her representative to “(a) do anything that the representative considers necessary in relation to the personal care or health care of the adult, or (b) do one or more things in

²³⁸ Kerzner, Lana, 2011, Paving the way to full realization of the CRPD’s rights to legal capacity and supported decision-making: A Canadian perspective. Vancouver: CIC, p.38.

²³⁹ Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt.2.8 (Can.).

²⁴⁰ Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, p.1122.

²⁴¹ Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt.2.10 (Can.).

²⁴² Kerzner *supra* note 238, at p.38.

²⁴³ *Ibid.*, at p.38.

²⁴⁴ See Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt.2.12 (Can.).

²⁴⁵ See Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt.3.20 (Can.).

relation to the personal care or health care of the adult”, such as “(i) decide where the adult is to live and with whom, including whether the adult should live in a care facility; (ii) decide whether the adult should work and, if so, the type of work, the employer, and any related matters; (iii) decide whether the adult should participate in any educational, social, vocational or other activity; (iv) decide whether the adult should have contact or associate with another person; -- (vi) make day-to-day decisions on behalf of the adult, including decisions about the diet or dress of the adult; -- (viii) despite any objection of the adult, physically restrain, move and manage the adult and authorize another person to do these things, if necessary to provide personal care or health care to the adult.”²⁴⁶ A consultation with a lawyer is required to create a Representation Agreement with the powers of section 9. The lawyer ensures that the person fulfils the capacity requirement of section 10. Stainton notes that the result of this provision is that persons with severe intellectual disabilities are excluded from using the powers of section 9.²⁴⁷

The Nidus Personal Planning Resource Centre and Registry (Nidus) in British Columbia operates a voluntary Registry for personal planning documents.²⁴⁸ The Registry facilitates the practice of supported decision-making as third parties are able to check the appointment of a representative and the wishes of the individual.²⁴⁹ A microboard is the second model that was established in British Columbia in 1990.²⁵⁰ Microboards consist of at least five people who are friends and family members of the supported person and joined together with her or him to form a non-profit society.²⁵¹ A microboard supports the individual in decision-making, monitors the supports, and aims to connect the person with their community. Nowadays there are approximately 900 microboards in the British Columbia. The development of microboards and support with their establishment is provided free of charge by the non-profit Vela Microboard Society.²⁵²

²⁴⁶ Ibid., at pt.2.9 (Can.).

²⁴⁷ Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, Research and Practice in Intellectual and Developmental Disabilities, pp.5-6.

²⁴⁸ Ibid., at pp.8-9.

²⁴⁹ Nidus, Personal Planning Resource Centre and Registry, http://www.nidus.ca/?page_id=238 (last accessed 30.03.2016).

²⁵⁰ Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, Research and Practice in Intellectual and Developmental Disabilities, p.8.

²⁵¹ For more information, see the Vela Microboard Society of Canada, <http://www.velacanada.org/vela-microboards> (last accessed 30.3.2016).

²⁵² Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, Research and Practice in Intellectual and Developmental Disabilities, p.8.

3.4.2 Criticism

When examining the supports provided by the Province of British Columbia as a whole, it is questionable whether they are, in fact, the best practice to follow. Kohn, Blumenthal and Campbell argue that the support model of British Columbia is not compatible with the notion of supported decision-making.²⁵³ The RAA requires supporters to comply with the person's wishes "if it is reasonable to do so".²⁵⁴ In the same vein, supporters are required to consult the adult's wishes solely to "the extent reasonable".²⁵⁵ Persons with disabilities are not allowed to make "bad decisions" under this Act, as these decisions can be overridden by the Public Guardian.²⁵⁶ Shih-Ning Then states that "conceptual dishonesty" should be avoided and simply admit that systems such as the Representation Agreements in British Columbia do not grant full autonomy to adults with disabilities.²⁵⁷ These representation Agreements provide solely "restricted" autonomy, because only some of the decisions that are reached under the RAA will be legally recognized. A system of support that would be in line with the CRPD Committee's interpretation of Article 12, would remove limitations of complying with the person's wishes only "if it is reasonable to do so".²⁵⁸

The RAA can be perceived to actually empower a representative to act in a manner which is not consistent with the person's right to self-determination and autonomy.²⁵⁹ Nevertheless, it allows representatives to rely on determinations of "best interests" of the individual only as a last resort if the person's beliefs and values are unknown.²⁶⁰ This is great progress forward. Still, it must be reminded that the system in the British Columbia has retained the use of substituted decision-making as the Adult Guardianship Act 1996²⁶¹ continues to maintain the option of imposing guardianship on an individual who is considered to be lacking the necessary capability for decision-making.²⁶²

²⁵³ Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, p.1122.

²⁵⁴ Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt. 3.16 (Can.).

²⁵⁵ Ibid.

²⁵⁶ Booth Glen, Kristin, 2012, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, *Columbia Human Rights Law Review*, 44, p.148.

²⁵⁷ Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 *Sydney Law Review*, p.157.

²⁵⁸ Ibid, at p.157.

²⁵⁹ Kohn et al. supra note 253, at p.1122.

²⁶⁰ See Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt. 3.16 (Can.).

²⁶¹ The Adult Guardianship Act, RSBC 1996, c. 6.

²⁶² Arstein-Kerslake, Anna & Flynn, Eilionóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.8.

Certainly, the Representation Agreement Act can work as an inspiration for States around the world on their journey towards a legal model of supported decision-making. The monitor system, which is adopted by this Act, can generate further formulations among States parties to the CRPD when they consider the necessary safeguards. The key element of the RAA is that it presents an enforceable legal framework which is accessible to persons with cognitive disabilities to guarantee the right to exercise one's legal capacity and to receive support in the decision-making. Persons who cannot fulfil the traditional standard for capacity, are provided with the possibility to decide for themselves with the help of the Representation Agreement.²⁶³ However, the RAA is not a model example of supported decision-making in the sense that this concept is generally understood.

3.5 Hard cases and concerns

The application of supported decision-making can encounter several "hard cases" in a similar manner that the paradigm of substituted decision-making struggles in certain situations with the determinations of "best interests".²⁶⁴ A typical example of hard cases are situations where it is not possible to determine the person's will and preferences.²⁶⁵ In such cases the CRPD Committee guides States parties to use the "best interpretation" of the person's will and preferences.²⁶⁶ It is certainly not an easy task to identify the point at which determination of the person's will and preferences cannot be realized. It raises questions of who should make that decision and how it should be made. Moreover, it is important to determine how much support must be provided to a person before such a decision could be reached.²⁶⁷

Gooding argues that as the CRPD Committee included "rights" to be an element which must be respected when making the "best interpretation of a person's will and preferences", it can be used as a guidance to clarify the process of the "best interpretation". Situations might arise where an individual's rights conflict with the representative's

²⁶³ See Stainton, Tim, 2015, Supported decision-making in Canada: principles, policy, and practice, *Research and Practice in Intellectual and Developmental Disabilities*, pp.9-10.

²⁶⁴ Arstein-Kerslake & Flynn *supra* note 262, at p.14.

²⁶⁵ See Adrian Ward, 2011, Adults with Incapacity: Freedom and Liberty, Rights and Status: Part 1, 5 *Scots Law Times* 21.

²⁶⁶ Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, paragraph 21.

²⁶⁷ Gooding, Piers, 2015, Navigating the "Flashing Amber Lights" of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review* (accepted for publication), pp.14-15.

determination of the “best interpretation” of her wishes and preferences. Therefore, States are required to elaborate on the limits of the “best interpretation” –principle.²⁶⁸

Other common examples of hard cases of supported decision-making are cases where a person’s will and preferences might cause serious harm to the individual or to other people; as well as cases where a person’s will and preferences are in conflict. The CRPD Committee does not elaborate on these possibilities in the General Comment on Article 12, but legal scholars have provided some guidelines.²⁶⁹ Different legal systems have adopted different criteria for a state intervention to occur in cases where serious harm is concerned. These standards must be applied on an equal basis for everyone to be compatible with Article 12 of the CRPD.²⁷⁰ Arstein-Kerslake and Flynn argue that support persons do not have to respect the individual’s will and preferences if it would result in civil or criminal liability on them. The support person should in these situations intend to understand the reasons behind such will and preferences, and continue to provide the kind of support that is legal and acceptable.²⁷¹

A person’s will and preferences might conflict in some situations, which can be challenging for a support person to manage. An example could be when a person with stomach pain has a will to be free from pain, but a preference not to go to the doctor.²⁷² Which one of these two, will or preference, should be respected? Dignity of risk might be required to be included in the consideration, as well as the analysis from the previous paragraph about decisions which result in serious harm to the person.

A common and well-grounded concern regarding supported decision-making is the possibility of manipulation and undue influence by supporters.²⁷³ Exploitation and abuse have been present in the regime of guardianship and, therefore, it is feared that the support paradigm might create new opportunities for their occurrence.²⁷⁴ Manipulation can occur both as deliberate coercion and unconscious influence where the supporter does not

²⁶⁸ Ibid., at pp.14-15.

²⁶⁹ Arstein-Kerslake, Anna & Flynn, Eilíonóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.12.

²⁷⁰ Ibid., at p.13.

²⁷¹ Ibid., at pp.12-13.

²⁷² Ibid., at, p.14.

²⁷³ See Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 *Sydney Law Review*, p.160; Gordon, Robert M., The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making, 2000, 23(1) *International Journal of Law and Psychiatry* 61.

²⁷⁴ Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, pp.1137-1138.

purposively influence the decision-making process.²⁷⁵ Carney warns that informal support in decision-making, even though probably the most compatible form of support with the equality principle, is especially vulnerable to misuse if protective mechanisms are not established.²⁷⁶

Third parties must be able to verify that the support person is acting with the individual's consent to support her, as well as to challenge the support person if they have a reason to believe she or he is not respecting the will and preferences of the individual.²⁷⁷ The Registry of representation agreements in the Province of British Columbia is one example of possibilities to enable third parties to verify the identity of support persons. Michael Bach and Lana Kerzner have created an institutional framework for safeguards in supported decision-making which could work as a great starting place for policy makers.²⁷⁸

The General Comment on Article 12 of the CRPD Committee states that a person who is using support must be able to refuse and end the support relationship when she so decides. Historically, persons with cognitive disabilities have been paternalistically safeguarded and they have not had access to such rights before.²⁷⁹ Respecting the will and preferences of persons with disabilities does not signify ignoring possible dangers. States Parties are obligated to protect persons with disabilities from violence, exploitation and abuse according to Article 16 of the CRPD. Special attention must be directed at ensuring that the measures taken apply equally to persons with and without disabilities.²⁸⁰ Legal capacity of a person with disabilities cannot be restricted on grounds that do not restrict legal capacity of a person without disabilities.²⁸¹

²⁷⁵ Ibid., at p.1123;

²⁷⁶ Carney, Terry & Beupert, Fleur, 2013, Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making, 36 *University of New South Wales Law Journal* 175, p.200; Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, pp.1137-1138.

²⁷⁷ Ibid., at para.25(d).

²⁷⁸ See Bach, Michael & Kerzner, Lana, 2010, A new Paradigm for Protecting Autonomy and the Right to Legal Capacity, Toronto Law Commission of Ontario, pp.167-169.

²⁷⁹ Arstein-Kerslake, Anna & Flynn, Eilíonóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.9

²⁸⁰ Article 5, CRPD.

²⁸¹ Arstein-Kerslake, Anna & Flynn, Eilíonóir, (2015), The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law, *The International Journal of Human Rights* 20(4), p.9.

Undue influence may arise also from “deliberate deference by the principal decision-maker.”²⁸² However, every adult defers in decision-making to some extent to people they trust, and every adult is subject to manipulation and influence from people close to them.²⁸³ This should be taken into account so that the standards for state intervention will not be lowered for persons with disabilities in comparison to persons without disabilities. Moreover, supported decision-making is built on the foundation of “relational autonomy” which recognizes the central role of others in decision-making.²⁸⁴ Therefore, it can be difficult to separate decisions that are reached without undue influence from decisions which reflect the views of the support person.²⁸⁵ The CRPD Committee has given a definition of “undue influence” that aims to clarify how these situations could be discovered.²⁸⁶ Finally, it is worth reminding that safeguarding against abuse is problematic also in the traditional regime of substituted decision-making, such as in the guardianship arrangements.²⁸⁷

Other common concerns that have been raised regarding the paradigm of supported decision-making are: ensuring third party enforcement,²⁸⁸ the need to establish boundaries between different support arrangements,²⁸⁹ the question of whether to discard or maintain decision-making ability tests,²⁹⁰ the possibility of “responsibilisation” as governments transfer risks from the State to persons with disabilities,²⁹¹ “net-widening” in a sense that

²⁸² Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship? *Penn State Law Review*, Vol. 117, No. 4, p.1123.

²⁸³ Gooding, Piers, 2015, Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review* (accepted for publication), pp.15-16.

²⁸⁴ *Ibid.*, at p.16; Gordon, Robert M., The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making, 2000, 23(1) *International Journal of Law and Psychiatry* 61.

²⁸⁵ See Gordon, Robert M., The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making, 2000, 23(1) *International Journal of Law and Psychiatry* 61.

²⁸⁶ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.22.

²⁸⁷ Gooding *supra* note 282, at pp.17-18.

²⁸⁸ Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 *Sydney Law Review*, p. 164.

²⁸⁹ Gooding, Piers, 2015, Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns, *Human Rights Law Review* (accepted for publication), pp.18-19.

²⁹⁰ *Ibid.*, at p.21; Bach, M. & Kerzner, L., 2010, A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, Report to the Law Commission of Ontario; UN Committee on the Rights of Persons with Disabilities (CRPD), *General comment on Article 12: Equal recognition before the law*, 11 April 2014, CRPD/C/GC/1, para.25.

²⁹¹ Gooding *supra* note 288, at pp.28-29.

more persons might be captured within the realms of adult capacity law arrangements,²⁹² and the major gap in the literature on empirical research about the implementation of a supported decision-making model.²⁹³ Due to the lack of evidence it is difficult to know if supported decision-making is actually reaching its goals, and which models of support work best in practice.²⁹⁴ Carney and Beaupert join in these concerns while adding that without evidence, we remain unknowing about the implications of this “bricolage” that is created by the mixture of public/private and soft laws, social arrangements and civil society all involved in the paradigm of support.²⁹⁵

However, Gooding argues that we should not lose sight of the core of this paradigm shift that justifies the reform process of substituted decision-making.²⁹⁶ Arstein-Kerslake shares his view stating that “the prima facie inequality enshrined in legislation is sufficient evidence to demonstrate a need for reform to reach equality and compliance with human rights law.”²⁹⁷ If reflected from this view, the demand for “proving” whether a support model of universal legal capacity works, appears questionable.²⁹⁸ Moreover, evidence-based law is problematic also from a practical perspective as converting empirical legal studies into law has its own challenges.²⁹⁹

Questions also arise in relation to the notion of “dignity of risk”. From a human rights perspective, it can be both supported and opposed, depending on how well a person understands the situation and what kind of decisions are concerned. Perhaps the primary question here is, whether the comparison between a person who might not understand the risk (not even with supports) and a person who does understand, is fair when elaborating on the dignity of risk? How can we ensure that somebody understands the risk and possible

²⁹² Carney, Terry & Beaupert, Fleur, 2013, Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making, 36 *University of New South Wales Law Journal* 175, p.195; Gooding supra note 288, at p.31.

²⁹³ Gooding supra note, at p.31; Carney, Terry, 2014, Clarifying, Operationalising, and Evaluating Supported Decision Making Models, *Research and Practice in Intellectual and Developmental Disabilities*, 1:1, pp.46-47; Bigby, C., Douglas, J., & Whiteside, M., 2015, Processes and dilemmas in support for decision-making, Report to Scope, Melbourne: Living with Disability Research Centre, La Trobe University On- Line Repository.

²⁹⁴ Kohn, N.A., Blumenthal, J.A. & Campbell, A.T., 2013, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review*, Vol. 117, No. 4, p.1129; Carney supra note 292, at pp.49-50.

²⁹⁵ Carney & Beaupert supra note 291, at p.201.

²⁹⁶ Gooding supra note 288, at p.34.

²⁹⁷ Arstein-Kerslake, Anna, 2014, Restoring Voice to People: Realizing the Right to Equal Recognition Before the Law of People with Cognitive Disabilities, (PhD Thesis, National University of Ireland), p.4.

²⁹⁸ Gooding supra note 288, at pp.34-35.

²⁹⁹ See Rachlisnki, Jeffrey J., 2011, Evidence-based law, 96(4) *Cornell Law Review*, p.912; Donohue, John & Wolfers, Justin, 2005, Uses and Abuses of Empirical Evidence in the Death Penalty Debate, 58 *Stanford Law Review* 791, at pp.792-294.

consequences? Or is it necessary for us, in the first place, to be assured? It is different to experiment on everyday matters without understanding the risk than in relation to decisions that can have a serious adverse effect. Therefore, is paternalism acceptable in such situations or should we respect the legal capacity of the person if appropriate safeguards are in place?

Browning, Bigby and Douglas criticize the view that substituted decision-making should be completely abolished under Article 12 of the CRPD, as there will always be persons whose will and preferences cannot be found. They suggest accepting the fact that supported decision-making should coexist with substituted decision-making, and thus start examining how this should be realized in practice. Overall their argument, however, endorses supported decision-making and retains the option to use substituted decision-making only as a last resort. In addition to these aspects, they highlight the need to clarify the issue of how to assess mental capacity in this new support model where the concept of capacity has changed to embrace relational autonomy instead of self-sufficiency.³⁰⁰

Lastly, the concern about isolated individuals is required to be discussed in relation to supported decision-making, because this paradigm heavily relies on the informal networks of persons with disabilities. Individuals without such networks or available supporters risk becoming excluded from the scope of supported decision-making, unless States take measures to establish a possible network or provide a supporter for the person.³⁰¹

³⁰⁰ See Browning, M., Bigby, C., & Douglas, J., 2014, Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice, *Research & Practice in Intellectual & Developmental Disabilities*, 1(1), pp.41-43.

³⁰¹ Carney, Terry & Beaupert, Fleur, 2013, Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making, 36 *University of New South Wales Law Journal* 175, p.195; Kerzner, Lana, 2011, Paving the Way to Full Realization of the CRPD's Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective, Prepared for "From the Margins: New Foundations for Personhood and Legal Capacity in the 21st century," April, 2011, p.59; Then, Shih-Ning, 2013, Evolution and Innovation in Guardianship Laws: Assisted Decision-Making, 35 *Sydney Law Review*, pp.165-166.

4. Domestic implementation of Article 12 of the CRPD in Finland

4.1 General overview of the Finnish system of guardianship

In Finland adults can have their interests and affairs managed by the system of guardianship under the Guardianship Services Act (442/1999); by issuing a continuing power of attorney or a regular authorization; by making a living will and other contracts related to care; by commissions; by the service account between a client and a social office (“välitystili”); and by *negotiorum gestio* (management of business). Some of these other documents and contracts can be used only in urgent cases and temporarily, but others can work as an option to guardianship for adults, such as a continuing power of attorney.³⁰² However, these other options are not likely viable in practice for persons with intellectual disabilities.

Local Register Offices function as guardianship authorities, except in the Åland Islands where the State Provincial Office of Åland holds this position.³⁰³ Guardianship is primarily an organization that supervises the managing of financial matters and financial interests.³⁰⁴ Registry offices monitor the activities of guardians, but the supervision mainly concentrates on auditing the guardianship accounts. The monitoring also includes legal acts which are subject to authorization and can be made by a guardian on behalf of the principal if the guardian receives authorization from a Register Office.³⁰⁵ A guardian is usually appointed by a District Court, but Register Offices can appoint a guardian when special requirements are fulfilled. Guardians for adults are generally either public guardians who work as public employees at the Public Legal Aid Offices³⁰⁶ or private persons, such as family members or close relatives. A minor’s guardians are usually the child’s parents.³⁰⁷

The Guardianship Services Act (GSA) entered into force in 1999. Interestingly, the Act was never sent for consideration to the Constitutional Law Committee during its drafting phase. Tornberg argues that this is the reason behind the paternalistic approach of the GSA

³⁰² Tornberg, Johanna, *Edunvalvontaoikeus*, in Kuuliala, Matti & Tornberg, Johanna (Eds.), *Suomen edunvalvontaoikeus*, Helsinki: Talentum, p.4, 36.

³⁰³ Section 84(2) of the Guardianship Services Act.

³⁰⁴ Government Bill 146/1998 vp; 1.1§ of the Guardianship Services Act.

³⁰⁵ Tornberg supra note 302, at p.49.

³⁰⁶ The Public Legal Aid Offices can outsource these services to other service providers, such as municipalities, organisations or businesses. See Välimäki, Pertti, 2014, *Edunvalvontaoikeus*, Helsinki: Talentum, p.72.

³⁰⁷ Tornberg, Johanna, *Edunvalvontaoikeus*, in Kuuliala, Matti & Tornberg, Johanna (Eds.), *Suomen edunvalvontaoikeus*, Helsinki: Talentum, p.49

as it was not drafted in accordance with fundamental rights and human rights.³⁰⁸ The predecessor of the GSA, the Act on Guardianship 34/1898, had been in force since the beginning of the 20th century.³⁰⁹ The material change of the GSA was mainly to increase the graduality of guardianship in accordance with the principle of applying the least restrictive safeguard. Behind this reform was the Recommendation No. R (99)4 of the Council of Europe³¹⁰ which urged Member States to ensure that their legislation recognized flexible legal response to the different degrees and various situations of incapacity.³¹¹ The recommendation No. R (99)4 is a model example of the functional approach to legal capacity.

The GSA is based on the separation between a principal's financial matters and personal matters, which signifies that a guardian's power to represent a principal differs according to the nature of the matter.³¹² In addition, guardian's powers differ with respect to whether a principal is an adult or a minor. The main provision regulating a guardian's power to represent a principal in her financial matters is 29.1§ of the GSA, which states: "The guardian shall be competent to represent the ward in transactions pertaining to the ward's property and financial affairs, unless the appointing court has otherwise ordered or unless it has been otherwise provided elsewhere in the law."

The GSA does not allow restrictions on a principal's legal capacity regarding her personal matters. Consequently, such restrictions can be ordered solely to secure the principal's financial interests (18.1§). A guardian is competent to represent a principal in her personal matters only if the court has ordered so (8.1 and 29.2§), and if the principal, at the moment of making the decision, cannot understand the significance of the matter (29.2§).³¹³ A guardian has, thus, only secondary competence in matters that pertain to the principal's person, and in such cases there can never be a situation where a guardian and a principal would have a parallel competence. The assessment whether a principal is capable of understanding the matter is realized by a relevant person, for example, by a doctor in cases

³⁰⁸ Ibid., at pp.193-194.

³⁰⁹ See Tornberg, Johanna, 2012, *Edunvalvonta, itsemääräämisoikeus ja oikeudellinen laatu*, Rovaniemi: Lapin yliopistopaino, PhD Dissertation, pp. 170–175, 408–411.

³¹⁰ Recommendation No R(99)4 of the Committee of Ministers to member states on Principles Concerning The Legal Protection of Incapable Adults.

³¹¹ Principles 2 and 3, Recommendation No R(99)4 of the Committee of Ministers to member states on Principles Concerning The Legal Protection of Incapable Adults.

³¹² Helin, Markku, 2001, *Edunvalvojan päätösvallan rajoista*, *Lakimies* 6–7/2001, 1070–1088, at p.1074.

³¹³ See also section 42§ of the Guardianship Services Act which regulates that a guardian is required to make sure that the principal is provided with appropriate care and treatment in accordance with her needs. If a principal requires help with personal practical matters, these are taken care of by the social welfare services (Government Bill HE 146/1998 vp, p.31).

where the matter concerns consenting to a treatment. In addition to financial and personal affairs, the GSA includes also a non-exhaustive list of highly personal affairs which have been excluded completely from a guardian's competence, such as giving consent to marriage and making a will (29.3§). If a principal does not understand the significance of such a matter, it shall not be performed.³¹⁴

4.1.1 The significance of a principal's opinion

According to Saarenpää, the Guardianship Services Act recognizes six different forms of guardianship which differ from each other by the influence they have to the self-determination and legal capacity of a principal.³¹⁵ These different forms are: a guardian who supports the principal with certain matters; a guardian who supports the principal with all financial matters; a guardian as a co-decision-maker in certain matters; a guardian as a co-decision maker with all financial matters; a guardian who has capacity over the principal in certain matters; and a guardian who has capacity over the principal in all financial matters (plenary guardianship).³¹⁶

The least restrictive form of guardianship is when a guardian is appointed to help and support a principal (8§ of the Guardianship Services Act).³¹⁷ In practice, however, solely guardians who support a principal with certain matters or with all the financial matters (support guardians) are appointed. The system of guardianship with 6 different categories appears to shrink to solely two options: appointing a guardian or declaring a person incompetent. Saarenpää argues that the reason behind this is that the appointment of a support guardian has the same result as declaring a principal legally incompetent.³¹⁸ This is the result of the Supreme Court's interpretation of section 29.1§ of the GSA,³¹⁹ which declares that a guardian has general competence to act on behalf of the principal –

³¹⁴ Helin, Markku, 2001, Edunvalvojan päätösvallan rajoista, *Lakimies* 6–7/2001, 1070–1088, pp.1084-1088.

³¹⁵ See 29.1§ of the GSA and compare to the 14§ of the GSA: "The appointment of a guardian shall not disqualify the ward from self-administering his/her property or entering into transactions, unless otherwise provided elsewhere in the law."

³¹⁶ Saarenpää, Ahti, 2005, Edunvalvonta, jäämistö ja jäämistösuunnittelun mahdollisuudet, in Tepora J., Tulokas M., Vihervuori P., *Juhlajulkaisu Juhani Wirilander 1935-30/11-2005*, Helsinki : Suomalainen Lakimiesyhdistys, p.309.

³¹⁷ Välimäki, Pertti, 2014, Edunvalvontaoikeus, Helsinki: Talentum, p.9.

³¹⁸ Saarenpää, Ahti, 2012, Henkilö ja persoonallisuus oikeus, in Tammilehto, Timo, Oikeusjärjestys, Osa I, 8 edition, Lapin yliopiston oikeustieteellisiä julkaisuja, Series C 59, p.262.

³¹⁹ A guardian's competence in Section 29.1§ of the GSA is regulated as a general provision without taking into consideration the principal's capacity (the 6 different categories of guardianship).

irrespective of the principal's will.³²⁰ Therefore, even in cases where a guardian is appointed without restricting the principal's legal capacity, the guardian usually has competence to act on behalf of the principal regardless of the principal's consent.³²¹

Välimäki has also interpreted section 29.1§ of the GSA as providing a general and unlimited capacity to act for support guardians.³²² Saarenpää and Tornberg argue that this interpretation is against the fundamental rights of the principal as it *de facto* restricts the principal's legal capacity by sharing it with the guardian.³²³ Tornberg highlights that taking a human rights-based approach is especially important in guardianship law as it always influences a person's fundamental rights.³²⁴ There is a "duality" both in the GSA and in the case law, since despite emphasizing the respect for human rights and dignity, the Act has provisions which are incompatible with these rights, and the courts do not recognize human rights correctly in relation to the GSA.³²⁵

The aim of the GSA to respect a principal's autonomy can be seen in the principle to always apply the least restrictive safeguard (8§ and 18.3§ of the GSA) and in the possibility to limit a guardian's task to contain solely certain legal transactions, matters or property. Furthermore, a principal must be consulted before a guardian can be appointed (86§ and 73§) and a guardian must consult the principal when making decisions about her affairs as regulated in 43§ of the GSA.³²⁶ The Supreme Court's interpretation is result of the gap in the GSA concerning the significance of the principal's opinion. The Act does not include a provision that would regulate how to resolve disagreements between a principal and the guardian.³²⁷ However, Saarenpää argues that a principal's will is, in principle, crucial in cases where a guardian is appointed to solely support the principal.³²⁸

³²⁰ See the Judgment of the Supreme Court KKO:2005:2; Saarenpää, Ahti, 2005, Edunvalvonta, jäämistö ja jäämistösunnittelun mahdollisuudet, in Tepora J., Tulokas M., Vihervuori P., *Juhlajulkaisu Juhani Wirilander 1935-30/11-2005*, Helsinki : Suomalainen Lakimiesyhdistys, pp.309-310.

³²¹ Judgment of the Supreme Court KKO:2005:2.

³²² Välimäki, Pertti, 2008, Holhoustoimen pääpiirteet, Helsinki: WSOY Pro, pp.49 and 79.

³²³ See Saarenpää, Ahti, 2005, Edunvalvonta, jäämistö ja jäämistösunnittelun mahdollisuudet, p.309; Tornberg, Johanna, Edunvalvontaoikeus, in Kuuliala, Matti & Tornberg, Johanna (Eds.), Suomen edunvalvontaoikeus, Helsinki: Talentum, p.8.

³²⁴ Tornberg, Johanna, 2012, Edunvalvonta, itsemääräämisoikeus ja oikeudellinen laatu, Rovaniemi: Lapin yliopistopaino, PhD dissertation, pp.56-57. For the importance of a human rights-based approach, see e.g. the decision of the Parliamentary Ombudsman 27.1.2012 dnro 2709/4/10, where the guardian sold the principal's house without consulting first with the principal.

³²⁵ Tornberg supra note 323, at p.8.

³²⁶ Välimäki, Pertti, 2014, Edunvalvontaoikeus, Helsinki: Talentum, pp.17-18.

³²⁷ Tornberg, Johanna, Edunvalvontaoikeus, in Kuuliala, Matti & Tornberg, Johanna (Eds.), Suomen edunvalvontaoikeus, Helsinki: Talentum, p.6

³²⁸ Saarenpää, Ahti, 2000, Holhouksesta edunvalvontaan, Pohjois-Suomen tuomarikoulu, Julkaisuja 1–2/2000, Rovaniemi, alaviite 4, p.165.

Helin, on the other hand, while agreeing that Saarenpää's interpretation would be the most favorable for a principal's self-determination, considers it to be too difficult to be realized in practice of the guardianship. Instead, he argues that a principal does not have such a strong position in the current Guardianship Services Act. The principal's opinion receives attention in relation to the consultation obligation (43§) and the obligation to promote the principal's interests (1§). Helin highlights that the consultation obligation only concerns important matters to the principal and, moreover, the opinion of the principal is only considered as *information* to help analyzing how to proceed with the matter in the principal's best interests.³²⁹

Disregarding a principal's reasoned opinion can be an infringement that raises doubt whether the guardian is suitable for the task, and might create a responsibility to compensate for damages.³³⁰ A principal's opinion regarding the appointment of a guardian has both a procedural effect (whether guardianship can be instituted by a local Registry Office or a District Court) and a material effect (concerning the assessment of the case). If a principal objects to the appointment of a guardian, the appointment may still be made if "taking his/her state and need for a guardian into account, there is no sufficient reason for the objection."³³¹ In other words, guardianship can be imposed on a person who is considered to fulfil the criteria of this provision.

4.1.2 *De facto* restrictions on legal capacity

A principal's right to self-determination can be restricted also by *de facto* restrictions on the principal's capacity. Examples of such cases are sections 67.1§ and 31.2§ of the GSA. The GSA holds the publicity of appointing a guardian as a general rule (67.1§), which can stigmatize a person as incapable of managing her or his affairs. As a result, third persons may not willing to perform legal transactions with the principal without the guardian's acceptance. The other example concerns a guardian's obligation to notify the credit institution where the principal has an account about who has the right to use the account (31.2§). The whole initial setting implies to the credit institution that the principal is, per se, incapable of using the account, unless the guardian notifies otherwise. In addition to these examples, section 38§ of the GSA grants a guardian the competence to be in charge

³²⁹ Helin, Markku, 2001, Edunvalvojan päätösvallan rajoista, *Lakimies* 6–7/2001, 1070–1088, alaviite 5, pp.1072-1073 (emphasis added).

³³⁰ Ibid., at p.1073. For a discussion on the difference between guardian's competence (kelpoisuus) and mandate (toimivalta) in relation to the principal, see Helin, Markku, 2001, Edunvalvojan päätösvallan rajoista, *Lakimies* 6–7/2001, 1070–1088, pp.1071-1072.

³³¹ Section 8(2) of the Guardianship Services Act.

of the principal's bank account and to allow the principal to administer solely a reasonable amount of money. Consequently, even the "support" guardianship can influence a principal's right to self-determination in everyday life.³³²

4.2 A review of the Guardianship Services Act

By ratifying the CRPD in the near future, Finland is expected to adopt "all appropriate legislative, administrative and other measures" for the implementation of the rights provided in the CRPD, and to "take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against people with disabilities".³³³ With respect to legal capacity, this requires a critical review of the Guardianship Services Act to ensure that it recognizes and implements the rights set out in the Convention. This kind of review was conducted in Finland before the Parliament accepted the Convention, and it declares that Article 12 of the CRPD does not require legislative reforms in the Finnish legal system.³³⁴ This thesis examines the GSA from the view of the CRPD Committee as it is the authoritative interpreter of the Convention and, moreover, its interpretation appears to be the most in line with human rights of persons with disabilities. Therefore, a re-review of the GSA in the light of Article 12 of the CRPD will be conducted and mainly from the perspective of persons with intellectual disabilities.

According to the CRPD Committee, States parties should, first of all, abolish substitute decision-making regimes which deprive legal capacity and discriminate in purpose or effect against persons with disabilities. For this aim, States parties are urged to provide statutory provisions which guarantee the right to legal capacity on an equal basis for everyone. In the Finnish legal order, legal capacity is understood as universal only in relation to the other component of the notion: the capacity to be a holder of rights, which can never be limited or denied. The capacity to act³³⁵ can be restricted if the requirements

³³² See Tornberg, Johanna, 2012, *Edunvalvonta, itsemääräämisoikeus ja oikeudellinen laatu*, Rovaniemi: Lapin yliopistopaino, väitöskirja, pp.46-48.

³³³ Article 4(1) of the Convention on the Rights of Persons with Disabilities.

³³⁴ See Government Bill HE 284/2014 vp, p.45. Finland states that Article 12, through the lenses of literal interpretation, does not prohibit restricting the capacity to exercise rights of persons with disabilities, but the restriction cannot be discriminative in purpose or effect (Government Bill HE 284/2014 vp., p.42).

³³⁵ In Finland the concept of "legal capacity to act" includes two components: the capacity to exercise rights; and legal liability. A person can be legally liable without having capacity to act under the law. Therefore, the appointment of a guardian affects primarily the capacity to act and exercise rights. See Saarenpää, Ahti, 2015, *Henkilö- ja persoonallisuus oikeus*, in Niemi, Marja-Leena (Ed.), *Oikeus tänään*, Lapin yliopiston

of Article 8.1§ and 18§ of the GSA are fulfilled.³³⁶ The GSA has adopted a functional approach to legal capacity, which can be perceived from these provisions as they require that capacity must be evaluated according to the situation at the moment of performing a legal transaction, and the capacity to exercise rights cannot be restricted solely on the basis of a disability.³³⁷ Furthermore, guardianship can be constructed to each principal's needs.³³⁸

4.2.1 Restrictions on legal capacity

Article 12 of the CRPD demands that legal capacity is guaranteed on an *equal* basis to persons with disabilities.³³⁹ Discrimination is defined in Article 2 of the Convention. Legal scholars and the CRPD Committee have criticized the functional approach to legal capacity for having a discriminatory nature, because it is frequently regulated in a non-neutral manner permitting deprivations and restrictions on legal capacity solely to persons with cognitive impairments. A neutral functional approach to legal capacity would permit such restrictions to anyone who would be considered to be lacking the necessary capability to understand the nature and consequences of one's actions – without requiring the finding of an “impairment or disturbance in the functioning of the mind”.³⁴⁰

The GSA does not regulate further about the assessment of a person's mental capacity or even define “capacity”. Section 8.1§ solely states that a guardian can be appointed to a person who is incapable of managing her or his affairs due to: “illness, disturbed mental faculties, diminished health or another comparable reason”.³⁴¹ Häyhä has interpreted this provision as requiring that a person must be able to evaluate the consequences of her or his

oikeustieteellisiä julkaisuja. Sarja C, Rovaniemi, Lapin yliopisto, p.246; and Tornberg, Johanna, 2015, *Edunvalvontaoikeus*, in Kuuliala, Matti & Tornberg, Johanna (Eds.), *Suomen edunvalvontaoikeus*, Helsinki: Talentum, p.346.

³³⁶ See Häyhä, Juha, 1996, *Oikeuskelpoisuus*, in *Encyclopædia iuridica Fennica*, 3rd edition, Suomalaisen lakimiesyhdistyksen julkaisuja, C-sarja, nro.26, Suomalainen lakimiesyhdistys, Helsinki, pp.391-392; Välimäki, Pertti, 2014, *Edunvalvontaoikeus*, Helsinki: Talentum, p.140; Government Bill HE 284/2014 vp., p.41.

³³⁷ Häyhä supra note 336, at p.392; Government Bill HE 146/1998.

³³⁸ Section 8.3§ of the Guardianship Services Act.

³³⁹ For a further discussion, see Minkowitz, Tina, Submission to Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12, January 22, 2014, available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx> (last accessed 05.04.2016).

³⁴⁰ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.15; Arstein-Kerslake, Anna & Flynn, Eilionóir, 2014, The Support Model of Legal Capacity: Fact, Fiction or Fantasy?, 32(1) *Berkeley Journal of International Law*, pp.127-128.

³⁴¹ Section 8.1 of the Guardianship Services Act.

actions.³⁴² It appears that the GSA has conflated the notions of mental capacity and legal capacity in a manner prohibited by the CRPD Committee.³⁴³ Under the GSA a person who is considered to have impaired decision-making skills, can have her capacity to exercise rights restricted or even removed if this impairment might cause harm to her financial interests.³⁴⁴ This clearly reflects a paternalistic approach and could be a violation against Article 12.2 of the CRPD taken in conjunction with Articles 2 and 5 of the CRPD, because it specifically requires the finding of “disturbed mental capacity”.

This can be seen as discriminatory in effect against persons with cognitive disabilities. According to the international doctrine on indirect discrimination, indirect discrimination is not unlawful if the criteria is used in order to achieve an acceptable objective and solely proportionate measures are used.³⁴⁵ The Finnish Government has considered that indirect discrimination is not unlawful under section 18.1§ of the GSA, since securing a person’s “financial affairs, property, livelihood or other important interests”³⁴⁶ is an acceptable objective.³⁴⁷ The reasoning of the Government Bill does not elaborate on the proportionality aspect. From the perspective of Articles 5 and 12 of the CRPD and the interpretation of the CRPD Committee, the traditional paternalistic approach should be replaced with the respect for the person’s will, rights and preferences. In this light, it is less certain whether the objective of the section 18.1§ of the GSA could be accepted as a lawful exception and the adopted measures as proportionate.

Moreover, the CRPD Committee considers that the universality of legal capacity should extend both to the right to be a holder of rights as well as to the capacity to exercise rights.³⁴⁸ In this light, the restrictions on a principal’s capacity to exercise rights which are allowed under the GSA, appear incompatible with Article 12 of the CRPD as they can be considered discriminatory. The most glaring example would be section 18.1§ which permits declaring a person incompetent as a last resort. Consequently, under the CRPD

³⁴² Häyhä, Juha, 1996, Oikeuskelpoisuus, in *Encyclopædia iuridica Fennica*, 3rd edition, Suomalaisen lakimiesyhdistyksen julkaisuja, C-sarja, nro.26, Suomalainen lakimiesyhdistys, Helsinki, p.392.

³⁴³ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.13-15.

³⁴⁴ Sections 8.1§ and 18§ of the Guardianship Services Act; See also Government Bill HE 146/1998 vp holhouslainsäädännön uudistamiseksi, p.36, which states that such harm and danger to the principal’s financial affairs and interests could be realized mainly when it is known that a principle might actively intent to, for example, take on debt or sell her property.

³⁴⁵ Government Bill HE 284/2014 vp., p.43.

³⁴⁶ Section 18.1§ of the Guardianship Services Act.

³⁴⁷ Government Bill HE 284/2014 vp., p.43.

³⁴⁸ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.14.

Committee's interpretation of Article 12, Finland should replace such provisions with statutory language which guarantees the right to legal capacity on an equal basis for everyone. Article 12(3) of the Convention establishes obligation for States parties to provide access to support for exercising legal capacity. The CRPD Committee urges States parties to provide a wide range of support which is based on respecting the rights, will and preferences of persons with disabilities. Furthermore, such support should fulfil the criteria of paragraph 29 of the General Comment on Article 12.³⁴⁹

4.2.2 Support to exercise legal capacity

When examining the Guardianship Services Act as a whole from the perspective of the new “support paradigm”, it becomes clear that the “support guardian” is the only form of the 6 categories of guardians of the GSA which, at first sight, could be compatible with Article 12 of the CRPD. A support guardian's role is limited to only support a principal with managing her or his financial affairs without restricting capacity to exercise rights. A support guardian's role can also cover a principal's personal affairs if so ordered by the court.³⁵⁰ Before analyzing the nature of the support given by “support guardians” in the light of Article 12 of the CRPD, it must be reminded that the case law has interpreted section 29.1§ of the GSA as granting general competence to support guardians to act on behalf of the principal regardless of her consent. Therefore, even though formally the least restrictive model of the 6 categories of guardianship is applied, in practice such guardians act according to a considerably more restricting competence.

The appointment of a support guardian causes also other *de facto* restrictions on a principal's capacity to exercise rights, which are based on specific provisions in the GSA.³⁵¹ Consequently, it appears that the role of a support guardian is not limited to only support and help a principal. Not only can they act on behalf of a principal without the principal's consent, but they are also guided by the principle of “best interests” instead of securing the principal's will, rights and preferences. Therefore, such guardians seem not to

³⁴⁹ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.50.

³⁵⁰ See Section 8§ of the Guardianship Services Act; Saarenpää, Ahti, 2005, Edunvalvonta, jäämistö ja jäämistösuunnittelun mahdollisuudet, in Tepora J., Tulokas M., Vihervuori P., *Juhlajulkaisu Juhani Wirilander 1935-30/11-2005*, Helsinki : Suomalainen Lakimiesyhdistys, p.309.

³⁵¹ See 31.2§, 38§ and 67.1§ of the Guardianship Services Act.

be compatible with the “support persons” envisioned in the CRPD Committee’s interpretation of Article 12 of the CRPD.³⁵²

Moreover, the GSA does not regulate about the significance of a principal’s opinion.³⁵³ Legal scholars have differing views regarding the question of how much weight such opinion should have to a guardian’s decision-making, whereas the Supreme Court has declared that a guardian’s competence is not reliant on a principal’s consent.³⁵⁴ Article 12 of the CRPD obligates States parties to provide a system of support which is based on the consent of the person. Support to exercise legal capacity should never be imposed on a person against her or his will.³⁵⁵

The regime of guardianship in Finland appears not to have been created in order to maximize a person’s abilities to decide for themselves, but to protect her or his property and other financial interests from her “destructive” actions.³⁵⁶ In other words, the GSA has adopted the paradigm of a principal’s “best interests” and the respect for a principal’s will does not have such strong protection. Furthermore, the opinion of a principal is consulted only if the matter is considered to be important for the principal and it can be realized without undue hardship.³⁵⁷ Tornberg points out that the interests, which are safeguarded by the Act, are not in various cases even the principal’s interests, but a guardian’s, the Guardianship Authority’s or some third person’s interests.³⁵⁸

Support in line with Article 12(3) of the CRPD would assist the supported person to decide for herself, instead of a guardian making the decision on behalf of her and in her “best interests”. Therefore, the supported person would *always* be not only consulted, but the main actor in the decision-making process. Section 43.2§ of the GSA provides that if a principal does not understand the significance of the matter, consulting her or him is not necessary. Neither this provision nor the preparatory work of the GSA elaborate further on

³⁵² See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.17; See also Tornberg, Johanna, Edunvalvontaoikeus, in Kuuliala, Matti & Tornberg, Johanna (Eds.), Suomen edunvalvontaoikeus, Helsinki: Talentum, pp.10-11; Saarenpää, Ahti, 2015, Henkilö- ja persoonallisuus oikeus, in Niemi, Marja-Leena (Ed.), Oikeus tänään; Lapin yliopiston oikeustieteellisiä julkaisuja, Sarja C, Rovaniemi: Lapin yliopisto, s. 256.

³⁵³ See section 43§ of the Guardianship Services Act; and Government Bill HE 146/1998 vp holhouslainsäädännön uudistamiseksi, p.51, which supports the view that a principal’s will does not enjoy strong protection under the system.

³⁵⁴ KKO:2005:2, para. 9.

³⁵⁵ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.20-21.

³⁵⁶ Sections 1§, 8§ and 18§ of the Guardianship Services Act.

³⁵⁷ Section 43§ of the Guardianship Services Act.

³⁵⁸ Tornberg supra note 352, at pp.193-194.

how the assessment of whether a principal understands the meaning is realized in practice. However, the Government Bill (HE 146/1998) of the GSA states that the neglect of hearing a principal before making a decision does not affect the validity of the performed legal transaction, or cause any actual sanction on the guardian.³⁵⁹ Article 12(3) of the CRPD requires that various supports are provided to a person who appears to not understand the meaning of a matter. If after exhausting all efforts (i.e. the person is not only consulted, but supported and assisted) it becomes clear that the person is not able to decide for herself and a decision must be taken, then the decision would be taken on behalf of her as a last resort, e.g. by using “facilitated decision-making” which respects the person’s will and preferences.³⁶⁰

All in all, it becomes clear that the regime of guardianship in the GSA does not respect a principal’s will, rights and preferences in the manner obligated by Article 12 of the CRPD. A principal can be bound to the actions taken by a guardian even if the principal objects to them; the capacity to exercise rights can be restricted and even deprived in a discriminatory manner;³⁶¹ the regime of guardianship can be imposed on her against her will; her right to self-determination is restricted *de facto* even by the appointment of a “support guardian”; and moreover the whole regime is not based on respecting principal’s will, rights and preferences, but on safeguarding her objective best interests.³⁶² A principal can easily become a mere object to her guardian; and if she becomes too active, her capacity to exercise her rights can be restricted. In order to reform the guardianship in the GSA into a system of supported decision-making, the attention should be moved from the principal’s deficits to all the possible supports which could be provided to empower her to take charge of her life. In addition, receiving support should not depend on a person’s mental capacity assessments, but on new non-discriminatory indicators.

The supervision of guardians by the Guardianship Authority is mainly concentrated on checking the accounts of a principal once a year and controlling the realization of certain significant legal transactions which require a permission by the local Register Offices.

³⁵⁹ See Government Bill HE 146/1998 vp holhouslainsäädännön uudistamiseksi, p.51.

³⁶⁰ The concept of facilitated decision-making was created by Michael Bach & Lana Kerzner in their paper: A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, Law Commission of Ontario (Oct. 2010), available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>.

³⁶¹ An incompetent person can only enter into transactions which are usual and of little significance; and administer income which she/he has earned during the incompetency (sections 24-25§ of the Guardianship Services Act).

³⁶² See Tornberg, Johanna, Edunvalvontaoikeus, in Kuuliala, Matti & Tornberg, Johanna (Eds.), Suomen edunvalvontaoikeus, Helsinki: Talentum, p.6.

This form of safeguard is not constructed to protect the will and preferences of principals, but to protect their (financial) interests. Furthermore, it is questionable whether even such interests are well protected under the current system. When taking into account the amount of principals there are per one guardian in Finland,³⁶³ it is difficult to see how guardians could be able to interact appropriately with their principals; consider the individuality of each case and investigate everyone's best interests when making decisions.³⁶⁴

Consequently, as the system already has challenges with individuality and safeguarding principal's interests due to the lack of resources, it is unlikely that supported decision-making could be incorporated into such a regime without considerable changes. In addition, the obligation to provide support of the CRPD does not limit itself to financial matters of supported persons. Support must be available also in relation to, e.g. personal health, education and housing. The resources of the "support guardians" of the GSA hardly extend to such areas. The whole approach of safeguards for the support in the exercise of legal capacity should be to secure the respect for a principal's will, rights and preferences.³⁶⁵ The Guardianship Authority's current supervision does not fulfil the obligations of Article 12(4) of the CRPD.

When examining all these different aspects as a whole, it is possible to conclude that the Guardianship Services Act is not compatible with Article 12 of the CRPD as interpreted by the CRPD Committee. Sirkka Sivula, Johanna Tornberg and Jukka Kumpuvuori, have also urged reforming the GSA in order to meet the requirements of Article 12 of the CRPD.³⁶⁶ The CRPD Committee has issued a concluding observation to Sweden in which the Committee notes that Sweden's legal capacity legislation continues to allow substituted decision-making and recommends that Sweden replaces such system with supported

³⁶³ In the Helsinki unit's service area of the local Register Office of Uusimaa, every public guardian had approximately 105 principals to take care of in 2014. See Tornberg, Johanna, *Edunvalvontaoikeus*, in Kuuliala, Matti & Tornberg, Johanna (Eds.), *Suomen edunvalvontaoikeus*, Helsinki: Talentum, pp.35-36.

³⁶⁴ See Sivula, Sirkka, 2010, *Tuettu päätöksenteko ratkaisuna oikeusturvan ongelmiin*, in Marja Pajukoski (Ed.) *Pääseekö asiakas oikeuksiinsa?* Sosiaali- ja terveydenhuollon ulkopuoliset tekijät -työryhmä Raportti III, p.112.

³⁶⁵ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.20-22.

³⁶⁶ See Sivula, Sirkka, 2010, *Tuettu päätöksenteko ratkaisuna oikeusturvan ongelmiin*, in Marja Pajukoski (Ed.) *Pääseekö asiakas oikeuksiinsa?* Sosiaali- ja terveydenhuollon ulkopuoliset tekijät -työryhmä Raportti III, p.111; and Tornberg, Johanna, *Edunvalvontaoikeus*, in Kuuliala, Matti & Tornberg, Johanna (Eds.), *Suomen edunvalvontaoikeus*, Helsinki: Talentum, pp.10-11; see also Saarenpää, Ahti, 2015, *Henkilö- ja persoonallisuus oikeus*, in Niemi, Marja-Leena (Ed.), *Oikeus tänään*; Lapin yliopiston oikeustieteellisiä julkaisuja, Sarja C, Rovaniemi: Lapin yliopisto, s. 256; Kumpuvuori, Jukka, *Tuetun päätöksenteon kehittäminen Suomessa*, Report to the Ministry of Social Affairs and Health, December 2010.

decision-making, which respects the person's will, rights and preferences.³⁶⁷ In this respect, it is likely that the CRPD Committee expects also Finland to replace the current guardianship regime to a system which is more compatible with Article 12 of the CRPD. This reform process should actively involve persons with disabilities through their representative organizations. Additionally, the Committee recommends States parties to conduct research of best practices of supported decision-making in order to discover the best models for each jurisdiction.³⁶⁸

4.3 Recognition of supports in Finland outside the system of guardianship

The Finnish legal order does not yet recognize a complete system of support to persons with disabilities in the exercise of legal capacity. However, there are separate statutory provisions which require providing support and guidance for vulnerable people in certain situations.³⁶⁹ The service guidance and authority's obligation to provide advice³⁷⁰ are a good example. The new Social Welfare Act (1301/2014) regulates that particular attention must be given at providing guidance and advising persons with special needs.³⁷¹ Sivula reminds that providing such advice may not always be impartial if the person giving the advice is, e.g., the decision-maker on the principal's case.³⁷² Moreover, authorities do not always respect in practice the obligation to provide advice.³⁷³ The administrative Procedure Act allows the use of an assistant during the process in the authority,³⁷⁴ which can also be seen as a form of support.

The Act on Services and Assistance for the Disabled (1987/380) regulates about the right to receive a personal assistant to help a person with severe disabilities with matters she or he is not able to realize on her own.³⁷⁵ The support provided by this service could function as supported decision-making if some changes were made. The current practice excludes

³⁶⁷ Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Sweden, Committee on the Rights of Persons with Disabilities (CRPD), 11th Sess., UN Doc. CRPD/C/SWE/CO/1 (31 March–11 April 2014), para.33-34.

³⁶⁸ See UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.50.

³⁶⁹ See Kumpuvuori, Jukka, Tuetun päätöksenteon kehittäminen Suomessa, Report to the Ministry of Social Affairs and Health, December 2010, p.14; Sivula, Sirkka, 2010, Tuettu päätöksenteko ratkaisuna oikeusturvan ongelmiin, in Marja Pajukoski (Ed.) *Pääseekö asiakas oikeuksiinsa?* Sosiaali- ja terveydenhuollon ulkopuoliset tekijät -työryhmä Raportti III, p.110.

³⁷⁰ Section 8§ of the Administrative Procedure Act 434/2003.

³⁷¹ Section 6§ of the Social Welfare Act (1301/2014). See also e.g. 5§ of the Act on the Status and Rights of Social Welfare Clients (812/2000); and 5§ of the Act on the Status and Rights of Patients (785/1992).

³⁷² Sivula supra note 369, at p.110.

³⁷³ Kumpuvuori supra note 369, at p.17.

³⁷⁴ Section 12§ of the Administrative Procedure Act.

³⁷⁵ 8c§ of the Act on Services and Assistance for the Disabled (1987/380).

persons who are not able to express the content of the help and the manner in which the help would be given to them.³⁷⁶ According to the CRPD Committee supported decision-making must be provided to everyone including persons with high support needs.³⁷⁷

The Act on Special Care for Mentally Handicapped Persons (519/1977)³⁷⁸ includes a possibility to receive a support person. Support persons have mainly helped with free-time activities, but there is great potential with this service in the light of the CRPD. The operation of support persons is organized by the third sector and based on volunteers. The status of a support person is not regulated clearly enough in the Act so this would be one of the first required changes.³⁷⁹ The Act on the Interpreting Services for Persons with Disabilities (2010/133) provides interpreting services for persons who have hearing impairment, combined hearing and vision impairment or visual impairment.³⁸⁰ The prerequisite for receiving this service is that a person is able to express her or his will and uses some functioning communication method.³⁸¹ There is some potential in this form of support as well and it appears to cover wider scope of persons than the service of personal assistance.³⁸²

It is possible that different services and supportive measures could be realized at the same time and together form the kind of support envisioned in Article 12 of the CRPD.³⁸³ However, there are various risks related to this approach as, for example, a person may not be granted the requested services in the first place. Secondly, the nature of support that these different services can provide might not fulfil the criteria of Article 12 of the CRPD. Therefore, creating a comprehensive system of supported decision-making would be the best solution.³⁸⁴ It could be established on the side of the current regime of guardianship

³⁷⁶ 8c§ of the Act on Services and Assistance for the Disabled (1987/380); Sivula, Sirkka, 2010, Tuettu päätöksenteko ratkaisuna oikeusturvan ongelmiin, in Marja Pajukoski (Ed.) *Pääseekö asiakas oikeuksiinsa?* Sosiaali- ja terveydenhuollon ulkopuoliset tekijät -työryhmä Raportti III, p.112.

³⁷⁷ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.29.

³⁷⁸ The name of this Act, by itself, reveals how old this Act is.

³⁷⁹ See Sivula, Sirkka, 2010, Tuettu päätöksenteko ratkaisuna oikeusturvan ongelmiin, in Marja Pajukoski (Ed.) *Pääseekö asiakas oikeuksiinsa?* Sosiaali- ja terveydenhuollon ulkopuoliset tekijät -työryhmä Raportti III, p.112; Kumpuvuori, Jukka, Tuetun päätöksenteon kehittäminen Suomessa, Report to the Ministry of Social Affairs and Health, December 2010, p.116.

³⁸⁰ Section 5§ of the The Act on the Interpreting Services for Persons with Disabilities (2010/133).

³⁸¹ Ibid., at section 5§.

³⁸² Ibid., at section 6§.

³⁸³ Kumpuvuori supra note 379, at p.15.

³⁸⁴ Sivula supra note, at p.14.

or, in the best outcome, to replace it.³⁸⁵ As supported decision-making concerns other persons as well besides persons with intellectual disabilities, regulating a general law which reaches everyone in need of such support would be recommendable.³⁸⁶

A working group of the Ministry of Social Affairs and Health gave 16.04.2015 a law proposal for a new disability Act (the Act concerning special services of persons with disabilities)³⁸⁷ to the Minister of Health and Social Services in the Finnish Government. The new Act would combine the Act on Special Care for Mentally Handicapped Persons and the Act on Services and Assistance for the Disabled.³⁸⁸ The proposed section 10§ of this Act regulates about the new services of training and support, which the municipalities must provide according to the individual need of the person in her cognitive skills, functional skills and social interaction skills.³⁸⁹ According to the proposed point 4 of the first paragraph of section 10§, persons with disabilities who have deficits in cognitive skills, can receive support in decision-making. The objective is to enable persons with cognitive disabilities to make choices regarding their own life. The support in decision-making includes, e.g. explaining the meaning of matters; support to evaluate different solutions when making decisions, and support to express feelings and wishes. Support would be available for the evaluation of service needs and for the planning of services; as well as for the important decisions (e.g. regarding one's housing or health) and small everyday decisions.³⁹⁰

The Government Bill of the Act concerning special services of persons with disabilities, is supposed to be given to Parliament in autumn 2017.³⁹¹ In case the Government Bill maintains the text of the proposed provision 10§, it appears promising that Finland will have in the near future a statutory provision providing the right to receive supported

³⁸⁵ Sirkka Sivula and Jukka Kumpuvuori have proposed different ways to incorporate the support paradigm into the Finnish legal order. See Sivula, Sirkka, 2010, Tuettu päätöksenteko ratkaisuna oikeusturvan ongelmiin, in Marja Pajukoski (Ed.) *Pääseekö asiakas oikeuksiinsa?* Sosiaali- ja terveydenhuollon ulkopuoliset tekijät -työryhmä Raportti III, pp.115-119; Kumpuvuori, Jukka, Tuetun päätöksenteon kehittäminen Suomessa, Report to the Ministry of Social Affairs and Health, December 2010, pp.29-30.

³⁸⁶ Sivula supra note 385, at p.115.

³⁸⁷ See final report of the working group,

http://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/70354/URN_ISBN_978-952-00-3582-2.pdf?sequence=1.

³⁸⁸ Press release of the Government, http://valtioneuvosto.fi/artikkeli/-/asset_publisher/tyoryhma-ehdottaa-vammaiset-henkit-saisivat-palvelut-toimintakyvyn-haitan-perusteella?_101_INSTANCE_3wyslLo1Z0ni_groupId=1271139.

³⁸⁹ Final report of the working group,

http://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/70354/URN_ISBN_978-952-00-3582-2.pdf?sequence=1, p.104-105, 148.

³⁹⁰ Ibid., at p.106

³⁹¹ For more information, see <http://stm.fi/vammaislainsaadannon-uudistus>.

decision-making. It is too early to assess more profoundly about the compatibility of this provision with the support model of Article 12 of the CRPD, but certainly it is a great and long-awaited step forward.

4.4 Recognition of reasonable accommodation in decision-making

States Parties to the CRPD are required, in addition to providing access to support under Article 12(3), to ensure that reasonable accommodation is realized to people with disabilities in the decision-making process. The Convention declares that non-discrimination includes the right to reasonable accommodation in the exercise of legal capacity, unless it is disproportionate or undue burden.³⁹² According to the CRPD Committee, such adjustments could be, for example, access to relevant buildings, accessible information related to decisions which have legal effect, and personal assistance.³⁹³

In the Finnish legal order, the right to reasonable accommodation for persons with disabilities has been regulated in the Non-Discrimination Act (1325/2014). Section 15§ of this Act states that “authorities, education providers, employers as well as providers of goods and services must realize necessary and appropriate modification and adjustments, where needed in a particular case, to ensure to persons with disabilities the access to authorities; and to receive education, employment, and generally available goods and services; as well as to manage work assignments and to advance in one’s career on an equal basis with others”. Section 8.2§ regulates that discrimination includes denial of reasonable accommodation.³⁹⁴

Although this provision does not specifically mention support in decision-making as part of reasonable accommodation, it can be interpreted to include it. The Government Bill (HE 19/2014 vp) states that section 15§ has been regulated taking into account the CRPD and its obligation to provide reasonable accommodation.³⁹⁵ In the CRPD the concept of

³⁹² Articles 5(3) and 2, CRPD.

³⁹³ UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 1 – Article 12: Equal Recognition Before the Law, 19 May 2014, UN Doc. No. CRPD/C/GC/1, para.34.

³⁹⁴ See also section 6.1§ of the Constitution of Finland which affirms that “everyone is equal before the law”; and section 6.2§: “No one shall, without an acceptable reason, be treated differently from other persons on the ground of sex, age, origin, language, religion, conviction, opinion, health, disability or other reason that concerns his or her person.”

³⁹⁵ The Government Bill HE 19/2014 vp Hallituksen esitys eduskunnalle yhdenvertaisuuslaiksi ja eräiksi siihen liittyviksi laeiksi, p.79.

reasonable accommodation relates to all human rights and fundamental freedoms.³⁹⁶ Therefore, if it can be concluded that section 15§ of the Non-Discrimination Act aims to implement the obligation of Article 5(3) of the CRPD,³⁹⁷ it follows that the right to receive reasonable accommodation under section 15§ contains support in decision-making regarding decisions which have legal effect.

In addition to section 15§ of the Non-Discrimination Act, the Government Bill 96/2015 for reforming the Act on Special Care for Mentally Handicapped Persons (519/1977),³⁹⁸ contains a provision in section 42a§ which orders that the service and care plan of a person with intellectual disabilities must include information about reasonable accommodation to secure the full participation for the person. After these amendments to the Act on Special Care for Mentally Handicapped Persons (SCMHA) have come into force, Finland will have two separate provisions securing the right to reasonable accommodation. It can strongly be assumed that the point two of section 42a§ of the SCMHA covers also the right to receive support in decision-making, since it is crucial for the full participation.

³⁹⁶ Article 2, CRPD.

³⁹⁷ See Government Bill HE 284/2014 vp, p.28, which states that the reform of the Non-Discrimination Act will be realized taking into account the obligations of the CRPD, such as the issue of reasonable accommodation.

³⁹⁸ The Government Bill 96/2015 vp Hallituksen esitys eduskunnalle laiksi kehitysvammaisten erityishuollosta annetun lain muuttamisesta.

5. Conclusion

The purpose of this research was to examine the right to equal recognition before the law as regulated in Article 12 of the CRPD, and to focus especially on the system of supported decision-making. Finland can be expected to ratify the Convention later in this year or in the next year 2017. Consequently, this thesis explored also the Finnish regime of guardianship and the different forms of support available in decision-making, in order to assess the compatibility of this regime with the CRPD. The review of the domestic legislation was realized by following the CRPD Committee's authoritative interpretation.

An important aspect to understanding the totality of the CRPD is to understand the paradigm shift embodied by the Convention about the way persons with disabilities are perceived by the world. This profound shift is closely related to the move from a charity/medical model of disability to a human rights model where the person with a disability is recognized as a rights holder and an active subject of law. Governments are expected to take measures to foster inclusive societies which accommodate the variety in human characteristics.

Article 12 is one of the most contentious and revolutionary articles in the CRPD. The CRPD illustrates an alternative way of understanding legal capacity by acknowledging that requiring support to exercise legal capacity does not signify incapacity. The CRPD Committee highlights that mental capacity and legal capacity must be perceived as two distinct concepts. Article 12 of the CRPD is groundbreaking as it introduces the right to access to support to exercise legal capacity which has never been before included in an international human rights instrument. States parties are required to provide necessary support that persons with disabilities might need to be able to decide themselves on matters that have legal effects. However, even day-to-day decisions may require exercising legal capacity for persons who live in institutions, group homes and other similar settings.

Article 12(3) of the CRPD does not further elaborate on what kind of "support" for the exercise of legal capacity the provision refers to. It appears that the drafters of the CRPD have given States parties the freedom to create the kind of structure and nature of support that best suit their jurisdiction. In any case, the provided support must fulfil the obligations enumerated in Article 12. Paragraph four of Article 12 regulates about the different

safeguards that must be established by the States parties. Although these safeguards must protect individuals from abuse, the protection must be provided on the same grounds as to persons without disabilities.

The text of Article 12 does not straightforwardly prohibit substituted decision-making. When taking into account the purpose of the CRPD, its context and the paradigm shift of legal capacity it embodies, it nevertheless becomes clear that the Convention as a whole endorses supported decision-making. Furthermore, various other articles of the CRPD require full legal capacity for their realization. The CRPD Committee states that the requirements of Article 12 of the CRPD are not met if regimes of substituted decision-making continue to exist in parallel with systems of supported decision-making.

All in all, it appears that the debate is not questioning the paradigm shift of legal capacity, but mainly the prohibition of using substituted decision-making as a last resort. The CRPD Committee's interpretation urges using the "best *interpretation*" of a person's will and preferences, where a decision is taken on behalf of the person. This approach is different to the traditional substituted decision-making as the person's will is at the center of the decision-making process instead of her objective "best interests". It is important for the States parties to recognize that Article 12 requires more than just reforming regimes of substituted decision-making. The fulfilment of obligations under Article 12 requires reform of various branches of domestic law, such as in contract law, criminal law and laws related to health care.

The chapter three of this research examined the system of supported decision-making. As a result of the CRPD, supported decision-making now has a basis in international human rights law. The concept of supported decision-making has different forms and several dimensions, such as: legal measures and informal measures; state action and measures of civil society; as well as different degrees and types of support. Additionally, it can be considered both as a process directed by the person, as well as an end, which legally recognizes the support that is provided, and gives legal standing to decisions that are made through such a process. Supported decision-making is often portrait as an opposite of substituted decision-making, where decisions are taken on behalf of a person and based on an objective assessment of her "best interests". The aim of supported decision-making is not solely to provide support with decision-making, but to support persons to exercise their legal capacity. Supported decision-making is, thus, more broadly about creating alternative

legal mechanisms, such as Representation Agreements and Microboards which will enable persons with disabilities to be in charge of their own lives.

Supported decision making is one *type* of support among others to exercise legal capacity. Regardless of the variety of systems of supported decision-making across the world, scholars have agreed upon certain common characteristics which must be present in such a system: (i) the individual is the primary decision-maker; (ii) the support is based on the person's consent and never imposed on her; (iii) the person is an active participator in the decision-making process; and (iv) decisions that are reached through supported decision-making are usually legally enforceable.

A common and well-grounded concern regarding supported decision-making is the possibility of manipulation and undue influence by supporters. Third parties must be able to verify that the support person is acting with the individual's consent to support her, as well as to challenge the support person if they have a reason to believe the support person is not respecting the will and preferences of the individual. In the chapter four of this paper the focus was on the domestic legislation in Finland. The Guardianship Services Act (442/1999) was explored in the light of Article 12 of the CRPD. The GSA is based on the functional approach to legal capacity, which aims to construct each guardianship to every principal's needs and prohibits restricting capacity to exercise rights solely on the basis of a disability. The GSA separates between a principal's financial matters and personal matters, which signifies that a guardian's power to represent a principal differs according to the nature of the matter.

The GSA recognizes six different forms of guardianship, but in practice solely support guardians are appointed or in the rare cases a person is declared incompetent. The review of the GSA revealed that the regime of guardianship in the Act does not respect a principal's will, rights and preferences in the manner obligated by Article 12 of the CRPD. A principal can be bound to the actions taken by a guardian even if the principal objects to them; the capacity to exercise rights can be restricted and even deprived in a discriminatory manner; the regime of guardianship can be imposed on her against her will; her right to self-determination is restricted *de facto* even by the appointment of a "support guardian"; and moreover the whole regime is not based on respecting principal's will, rights and preferences, but on safeguarding her objective best interests.

In the Finnish legal system the capacity to exercise one's rights can be restricted if the requirements of Article 8.1§ and 18§ of the GSA are fulfilled, which is the basis for the incompatibility with the CRPD Committee's interpretation of Article 12 of the CRPD. The most glaring example would be section 18.1§ which permits declaring a person incompetent as a last resort. The criteria for these restrictions can be considered discriminatory against persons with intellectual disabilities as they require the finding of "disturbance of mind". Even though such finding is not, per se, sufficient ground for restricting one's legal capacity, it can nevertheless cause discrimination in effect.

This argument is further supported by the realization that the GSA – or the Finnish legal order in general- does not provide appropriate support for the exercise of legal capacity. This is mostly due to the fact that the support given under the regime of support guardians follows primarily the approach of respecting the principal's objective "best interests" instead of her will, rights and preferences. Moreover, legal practice in Finland has interpreted the GSA in a manner that grants support guardians a general competence to act on behalf of the principal regardless of her or his opinion, even though their formal appointment concerns solely supporting and helping. When these factors are combined with the *de facto* restrictions on a principal's right to self-determination after the appointment of a support guardian, it seems like the support guardians of the GSA are not compatible with the criteria of Article 12 of the CRPD as interpreted by the CRPD Committee.

The examination of the GSA also revealed that the Guardianship Authority's current supervision does not fulfil the obligations of Article 12(4) of the CRPD. The supervision of guardians by the Guardianship Authority is mainly concentrated on checking the accounts of a principal once a year and controlling the realization of certain significant legal transactions which require a permission by the local Register Offices. This form of safeguard is not constructed to protect the will and preferences of principals, but to protect their (financial) interests. Moreover, the obligation to provide support in Article 12(3) of the CRPD does not limit itself to financial matters of supported persons. Support must be available also in relation to, e.g. personal health, education and housing. The resources of the "support guardians" of the GSA hardly extend to such areas.

Finland recognizes some supports outside the system of guardianship which could be used to support in decision-making as well, but the Finnish legal order does not yet have a

complete system of support. It is worth highlighting that at their current state none of these services or support measures are fully compatible with Article 12 of the CRPD. The Finnish legal order has separate statutory provisions which require providing support and guidance for vulnerable people in certain situations. A good example is the new Social Welfare Act 1301/2014. The existing services of personal assistance and volunteer “support persons” to persons with intellectual disabilities seem like the best platforms for the development of a system of supported decision-making – as long as they are reformed to fulfil the criteria of Article 12(3) of the CRPD. Personal assistants often work with their clients for a long period of time and, thus, learn to communicate with them and interpret their will. Appropriate safeguards must be put in place to protect the person with disabilities against abuse and other undue influence from the supporter.

All in all, creating a comprehensive system of supported decision-making would be the best form to incorporate supported decision-making in Finland. Currently, there is a reform process underway which aims to combine the Act on Special Care for Mentally Handicapped Persons and the Act on Services and Assistance for the Disabled. The emerging Act, the Act concerning special services of persons with disabilities, is proposed to contain a provision guaranteeing the right to receive support in decision-making in certain situations for persons with cognitive disabilities. The Government Bill is supposed to be given to Parliament in autumn 2017. In case the Government Bill maintains the text of the proposed provision, it appears promising that Finland will have in the near future a statutory provision providing the right to receive supported decision-making.

Even if substituted decision-making would be retained as a last resort after the emergence of supported decision-making in the Finnish legal order, the current system of guardianship would still need reforming in order to be compatible with the minimum requirements of Article 12 of the CRPD. The use of substituted decision-making as a last resort requires that all efforts are first exhausted to discover a person’s will and preferences, before a decision could be taken on behalf of her or him. In other words, different supports must be provided to a person with intellectual disabilities, such as plain language and a trusted support person. The GSA is not regulated upon this kind of construction of a person’s right to self-determination.

The GSA should be reformed to contain provisions that regulate about the strict obligation to discover and respect a person’s will and preferences, as well as to provide support for

the exercise of legal capacity. Support would be needed already in the first meeting with a guardian; i.e. before a guardian is even appointed. Furthermore, the principle of “best interests” should be replaced by respecting a person’s will, rights and preferences. Additionally to these aspects, the *de facto* restrictions on a principal’s right to self-determination which affect also principals who have a support guardian, must be abolished.

The paradigm shift in legal capacity has potential to completely transform our understanding of mental capacity and decision-making. It does not solely endeavor to improve the current regimes of guardianship in the name of human rights, but to challenge our thinking in relation to moral personhood and autonomy. It is time to begin this conversation in Finland as well.