

The Law as a Source of Stigma or Empowerment: Legal Capacity and Persons with Intellectual Disabilities

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Abstract

While the law is generally portrayed as a tool to combat stigma, outdated legal institutions continue to reinforce negative stereotypes about persons with intellectual disabilities. This chapter describes how guardianship is based on misconceptions regarding the abilities of persons with disabilities, and how these false assumptions lead to abuse and denials of autonomy. Supported decision-making is presented as an alternative approach that does not deny the agency of persons with disabilities, and in fact leads to strengthening their skills. In order to replace guardianship with supported decision-making, large scale social reform is necessary in which the law can play an important part. The widely ratified Convention on the Rights of Persons with Disabilities provides impetus for such legal reform.

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Introduction

When it comes to disability-related stigma, the law is often perceived as playing a positive role. Anti-discrimination and anti-harassment laws can protect persons with disabilities from unfair treatment. Constitutional provisions can serve to reinforce their dignity and equality by explicitly acknowledging their fundamental rights. Human rights treaties, especially the UN Convention on the Rights of Persons with Disabilities (CRPD, UN General Assembly, 2007), spell out human rights protections, with the CRPD taking the added step of requiring governments to tackle stigma and discrimination by, among others, raising awareness about persons with disabilities. Further, mainstream human rights bodies, such as the UN Human Rights Committee, have recently started to recognize the interests of persons with disabilities in formulating their jurisprudence and recommendations. Notably, the European Court of Human Rights held in 2010 in *Kiss v. Hungary* (2010) that persons with intellectual disabilities are a historically marginalized group who will benefit from strict scrutiny in the Court's jurisprudence.

The law is therefore often depicted to be on the side of persons fighting stigma and inequality. This chapter, however, argues that in reality the situation is more complicated. The law seemingly furthers the interests of persons with intellectual disabilities, but at the same time is also frequently the source of their stigmatization and exclusion. For although a plethora of legal instruments superficially help persons with intellectual disabilities, many established legal institutions build on centuries old stereotypes of these individuals as helpless and incapable objects of care rather than as persons with agency. These assumptions often are unstated and unrecognized. Yet they nonetheless motivate the daily interaction between the law and disability in a profound way, by reinforcing misperceptions that persons with intellectual disabilities are incapable and provide the means through which those individuals are socially disempowered and excluded.

The Case of Guardianship

To illustrate the general claim made above, this chapter describes how guardianship stigmatizes and violates the human rights of persons with intellectual disabilities globally on a daily basis. And yet to avoid the negative consequences of guardianship, we argue that even overtly recognizing the stigmatizing effects of the law is insufficient to counter their impact. Hidden and embedded assumptions of legal institutions must be uncovered, and new institutions created that build on positive imagery and presumptions regarding the agency and abilities of persons with intellectual disabilities. Only then can legal systems amend their daily practices and exert a positive influence on socio-legal perceptions of persons with intellectual disabilities. This chapter demonstrates how the CRPD provides an avenue for such legal reform by replacing guardianship with supported decision-making.

Guardianship is a legal institution that exists in some form or other in all countries of the world, conceivably to protect the interests of persons with disabilities who are unable to manage their own affairs (Nowak, 1993). It involves the limitation of a person's right to make legally valid decisions (the limitation of their *legal capacity*) and the authorization of another person (the guardian) to make decisions on the person's behalf. The newly *legally incapacitated* person loses the right to make decisions about their property and even their own body: about medical decisions, family matters such as care over their children, where they lives, who they associate with, and so on. These issues will now be decided by the person's guardian. Because incapacitation is obviously a severe interference with personal autonomy and integrity, guardianship is thought of as a measure of last resort which can be ordered only by a court (or another State-sanctioned administrative agency) and is utilized only for a narrow circle of persons with intellectual and psychosocial disabilities (the latter group is also referred to as individuals with mental disabilities).

Guardianship has changed little in its two thousand year history. On the surface, it is applied through a functional test and affects only those persons who are found by a medical assessment to lack capacity to make their own decisions. However, in practice, the main determinant of incapacitation is the existence of an intellectual (or psychosocial) disability (Dhanda, 2007). The person's actual skills or desires matter little (Szegeciné, 1982). Studies of guardianship systems have found that guardianship is overused in many countries (Salzman, 2011). In addition, most incapacitations result in plenary guardianship, the most severe form of guardianship, which restricts a person's rights to make decisions in all areas of life (MDAC, 2013).

The overuse of guardianship has serious effects on persons with intellectual disabilities (Kohn et al., 2013). First, individuals are denied legal capacity in areas where they may well be functionally capable of making decisions, including consent to medical treatment (Plesó v. Hungary, 2012), voting (Fiala-Butora et al., 2014), marriage, work, applying to courts (Salontaji-Drobnjak v. Serbia, 2009), and participation in adoption proceedings (X. v. Croatia, 2008). This is because courts undervalue their skills, and thus consider persons with intellectual disabilities as less capable than they in fact are.

Due to these legal limitations, it becomes much more difficult for a person with an intellectual disability to secure their interests. This is because the guardian has control over their life and is legally entitled to make decisions on the person's behalf. In consequence, it is enormously difficult, if not impossible, for the person to challenge the guardian's decisions. If they and their guardian disagree, it is the guardian's will which nearly always prevails (Salzman, 2011). Ironically and tragically, while guardianship is supposed to protect persons with disabilities from abuse, it makes abuse by guardians not only possible but commonplace (MDAC, 2013).

The denial of rights also has an important pedagogic (or anti-therapeutic) effect. When a person cannot exercise certain rights, or make certain decisions because they are made on their behalf by others, they gradually lose their functional ability to exercise rights in the respective areas (Kohn et al., 2013). As an empirical matter, the condition of persons under guardianship deteriorates, and it is rare for any of them to recover their decision making abilities once stripped of their legal capacity and precluded from exerting their agency (Salzman, 2011).

Guardianship is likewise an important social marker of lack of skills. It signals to others that the person is unable to make their own decisions and is associated with the severe inability of an individual. After all, if only the most incapable persons with intellectual disabilities are incapacitated, it follows that those under guardianship are severely disabled and unable to act on their own behalf.

Although the above misplaced correlation between guardianship and inability is widely believed, it is far from the truth. It is not uncommon for persons able to work, live alone or with a partner, and attending to all of their own affairs, to nevertheless end up under guardianship. Yet, strikingly, interviews conducted by the Hungarian Civil Liberties Union with persons under guardianship show that at times it is solely the placement under guardianship which reveals to others that the person has a disability. For example, one interviewee explained that her new neighbors did not notice she had a disability until they found out that she was not allowed to vote because she was under guardianship (HCLU, 2012). From that, the neighbors deduced that there must be 'something wrong' with her and her condition must be severe if courts thought it appropriate to appoint a guardian.

These examples are not merely the result of faulty applications of an otherwise well-designed legal system. Guardianship laws automatically produce inflated numbers of incapacitated persons. Of course, the degree of overuse varies across jurisdictions, but it

cannot be completely avoided. Even the best assessment tools will produce false incapacitations. Overuse is unavoidable in great part because the system is built on the presumption that persons with intellectual disabilities in general lack capacity to manage their affairs, and, in order to protect them, others need to make decisions on their behalves.

Guardianship laws play an important role in maintaining this long standing societal prejudice. Guardianship has institutionalized the idea that to help a person with an intellectual disability, their skills and abilities have to be supplanted. It creates persons who are objects of care by prohibiting them from helping themselves—from working, learning, marrying, and making decisions in general. Yet, persons with intellectual disabilities are not a socially marginalized population because of their disability; they are excluded from social participation in part through the operation of guardianship laws.

By treating persons with intellectual disabilities as objects of protection, and at the same time denying their agency, the law strengthens outdated stereotypes that lead to exclusionary practices. Thus, legal institutions aimed at helping persons with intellectual disabilities often harm them. The stigmatization this chapter addresses is not a necessary effect of otherwise beneficial measures, but rather an unintended and avoidable outcome. It is commonplace rather than rare that this system has serious problems and leads to many human rights abuses. The reason guardianship still exists is that there does not seem to be a better solution. Or, at least until recently, there has not been one.

The Alternative— Supported Decision-Making

For millennia, guardianship has been the only solution to help persons with decision-making difficulties. However, in recent years, substituted decision-making has emerged as an alternative. The concept was developed in the domestic laws of Sweden and Canada (Gordon, 2000), and received worldwide recognition during the negotiations of the CRPD, adopted in

2006. Article 12 of the CRPD requires that persons with disabilities exercise their legal capacity on an equal basis with persons without disabilities, which many argue means without any restrictions of their legal capacity (Minkowitz, 2010).

Supported decision-making rests on the notion that even though some persons with intellectual disabilities might have difficulties making decisions, those difficulties do not justify making decisions on their behalves (Carney, 2012). Instead, those individuals should receive assistance from supporters to make their own decisions (Bach & Kerzner, 2010), and that with such assistance they are able to make their own decisions (Dhanda, 2007). Indeed, this process is not all that different from how individuals without disabilities make decisions. With complicated issues such as buying a house or investing money, everybody relies on informal support of family, friends, experts in the area and other trusted persons (Lord & Stein, 2013). Persons with intellectual disabilities might require a higher level of support, even in areas where most people get along on their own or with a minimum of assistance (such as with shopping or cooking), but that is not a qualitatively different situation (Gordon, 2000). Guardianship law makes an arbitrary choice by labeling the use of support by persons with disabilities as a proof of incapacitation, but accepts support utilized by persons without disabilities as the natural consequence of fully autonomous and competent decisions.

The goal of legal reform, required by the CRPD, is to create a legal framework which validates the supported decisions of persons with intellectual disabilities. This is not an easy task since difficulties and embedded resistance arise from many quarters. Legislators, academics and advocates are, for example, debating how to protect supported persons from possible abuse, and how to incorporate persons with higher support needs who are arguably unable to make decisions even with support, into a support framework. The purpose of this chapter is not to give an overview of the possible solutions, something that has been done

elsewhere (Fiala-Butora, 2015), but to underline the connection between stigma and the law's treatment of legal capacity.

In contrast with guardianship, supported decision-making does not underestimate the abilities of persons with intellectual disabilities. It relies on whatever abilities they have, and strengthens their capacity by providing support. There are no legal restrictions on what a person with a disability is allowed to do; any emphasis is put on overcoming their lack of knowledge, experience and skills. This has an opposite pedagogic or therapeutic effect to guardianship: regardless of the starting position, the abilities of a person participating in supported decision-making should develop, rather than diminish as is common under guardianship.

There is a dearth of empirical evidence about whether supported decision-making can deliver on these promises in practice (Kohn et al. 2013). It is, however, clear that its legal design forces others to interact with the person with intellectual disability. They cannot be hidden in the background, or be made voiceless or invisible while others communicate with their guardian. By talking directly with the person with a disability, contracting parties form a personal and realistic impression about the person's skills – and they will have their supporters to ensure that they perform well in the process.

No doubt some persons with intellectual disabilities will find it difficult to take care of their own interests, especially if they were prevented from doing so in the past. Others will perhaps not receive the support they need. It is sure, however, that the underlying assumptions on which supported decision-making is built are much more favorable to persons with disabilities. It requires all involved to act on the assumption that persons with intellectual disabilities are able to make decisions given the opportunity and means, and thereby pushes legal transactions to reflect the idea of persons with intellectual disabilities as capable and equal actors.

How to Transform Legal Institutions – the Perspective of Stigma

Supported decision-making is already an existing practice in some countries of the world, such as Canada and Sweden, and is proliferating in others through legal reform. It is tempting to suggest that when existing guardianship laws are replaced with laws based on support, the underlying problems will be resolved. However, the challenge is much more difficult to meet as the stigma reflected in and created by the law is not easy to overcome.

Prejudices against persons with disabilities—and specifically, the widely held belief that persons with intellectual (and psycho-social) disabilities are unable to manage their own affairs—are deeply socially entrenched. For millennia these beliefs have manifested themselves in guardianship laws which precluded persons with disabilities to make decisions on their own. In a circular way, these laws also shaped societal conventions regarding the misperceived inability of people with disabilities. Thus, guardianship laws are not solely responsible for the image of a person with an intellectual disability as incompetent; the prejudice is older and much more entrenched.

The law is important, however, in the way prejudice against individuals with intellectual disabilities currently manifests. The guardianship system deprives many otherwise capable people of their legal capacity. They are considered incapable of independent life once they were placed under guardianship, even if they had been able to work and live alone before that legal procedure. Some persons may not even know for years that they are legally incapacitated: they continue to take care of themselves and go about their lives while in the eyes of the law they are considered incapable of having those very same independent lives (Sýkora v. the Czech Republic, 2012). Once rights are taken away from them, persons with intellectual disabilities gradually lose these skills, and guardianship becomes a self-fulfilling prophecy: those deprived of their legal capacity often become dependent on various forms of

assistance. Guardianship law, often arbitrarily administered, plays a key role in determining who becomes a totally incapable, severely disabled person in need of society's help, and in defining the nature of that dependency.

Nevertheless, and despite the unintended injurious effect, the law can also have a positive influence on societal attitudes. The task of systemic reform in this context is to put in place legal institutions that promote the image of persons with disabilities as equally capable and empowered with agency. However, abolishing all existing guardianship laws and replacing them with support mechanisms, while helpful, is insufficient. This is especially true for countries with an established guardianship system where the instantiated culture does not consider persons with disabilities as autonomous. In those States, social workers, medical professionals, public administration, guardians, and family members acting under current guardianship regimes, are all working under the view of persons with disabilities as objects of care rather than individuals with decision-making abilities. Simply abolishing guardianship will not immediately change that attitude. To the contrary, they would likely respond by reinventing the repressive institutional culture in a new legal framework by renaming 'guardianship' as 'supported decision-making'. Thus, even changing the criteria of guardianship so that it does not formally restrict legal capacity, is not enough.

Besides establishing a new general framework, legislators must also identify specific obstacles in which this institutional culture manifests itself, and directly overrule them. Safeguards must be put in place so that persons with disabilities can indeed make decisions which are currently most often denied to them. Hence, legal reform has to affect the way banks engage with their clients and offer loans, doctors talk to patients, child custody is exercised by parents, public administration handles customers, courts hear witnesses, and many other areas which currently constitute a direct obstacle to persons with disabilities exercising their legal capacity.

The law cannot in itself change embedded societal structures overnight. That is a much more complex task, requiring a longer period of time and other factors to be present. The law can and should, however, establish the structure and create the instruments to allow society to gradually accept and incorporate the notion that persons with disabilities can make their own decisions. By recognizing persons with disabilities as decision-makers under the law, supported decision-making forces all other actors to communicate with them instead of their guardians. Some will no doubt find this burdensome, but the law's normative goal should be to expand those areas where the wishes of persons with disabilities will be honoured rather than to exclude persons with disabilities from decision-making on the ground of administrative convenience. In this process it is crucial that we uncover the hidden assumptions that continue to undermine the equal place and legal capacity of persons with intellectual disabilities.

Conclusion

This chapter has argued that the stigmatizing effects of the law are not always evident. Legal institutions can directly contribute to building a positive image of persons with intellectual disability, by for example prohibiting open discrimination against them or expressly securing their fundamental rights. At the same time, legal institutions are built on incorrect assumptions about persons with intellectual disability. Through their daily operation they allow these prejudicial assumptions to influence the social environment. This negative effect is harder to observe, but nevertheless very damaging to the public perception of persons with intellectual disabilities.

Guardianship is an example of a widely used legal mechanism that is built on the idea of persons with intellectual disabilities as incapable of managing their own affairs. Due to more than two thousand years of guardianship laws, unfounded stereotypes regarding the

inability of persons with intellectual disabilities to make their own decisions has been deeply embedded across cultures. Family members, medical and legal professionals, service providers and all kinds of caregivers have learned to ignore the wishes of persons with intellectual disabilities, and instead to make decisions on their behalves, to preserve their 'best interests'.

Supported decision-making, a newly emerged alternative to guardianship, shows that protecting the human rights of persons with intellectual disabilities does not have to come at the cost of undermining their capacity and social perception. Stigmatization is not a necessary cost of help, but rather an obstacle to be overcome. Implementing supported decision-making will be a long process, because it requires changing societal norms about how to interact with persons with intellectual disabilities.

While this seems to be a daunting task, one must recall that existing prejudicial attitudes were to a great extent created and are maintained through the operation of guardianship laws. The law can therefore equally play a role in dismantling those social constructs. To achieve this goal, the task of legal reform should be to uncover hidden assumptions behind our legal institutions that covertly contribute to stigmatizing persons with intellectual disabilities. Guardianship serves as one example in this chapter. Similar seemingly disability-neutral mechanisms excluding persons with intellectual disabilities from equal participation can be found in other areas of the law, from labor law through criminal law to family law and other sectors (Fiala-Butora, 2013).

The CRPD provides an impetus for reexamining our institutions from a disability human rights perspective. It sets a high standard by requiring the full inclusion and equal participation of persons with intellectual disabilities in all areas of life. In many areas, it directly identifies the existing obstacles which until now went unnoticed by domestic legislators and courts. In others, it will be the task of self-advocates, supporters, legislators,

and academics to uncover and root out the outdated prejudices deeply embedded in our legal system.

Key learning points:

- Legal institutions can be based on prejudiced assumptions and have a stigmatizing effect on persons with intellectual disabilities.
- Guardianship is an example of a seemingly benign institution. It is based on a presumption that persons with intellectual disabilities are incapable of decision-making and reinforces this stereotype through its operation.
- Guardianship still exists because it is wrongly considered irreplaceable. However, supported decision-making has emerged as an alternative that strengthens the capacity of persons with intellectual disabilities instead of limiting their right to make decisions.
- To shift legal systems from guardianship to supported decision-making, current social norms and expectations need to be challenged. The law helped to create prejudiced attitudes and it can help change them as well.
- Legal reform should uncover hidden prejudice in laws and replace outdated institutions with new ones built on realistic and empirically founded understandings of persons with intellectual disabilities.
- The widely adopted CRPD provides good momentum for large-scale legal reform.

Accessible summary

- The law often treats persons with intellectual disabilities as unable to make decisions for themselves.

- Guardianship stops persons with intellectual disabilities from making their own decisions.
- Supported decision-making helps persons with intellectual disabilities to make their own decisions.
- We need to replace guardianship with supported decision-making. It is not easy, because many people are used to the old laws and think persons with intellectual disabilities cannot make their own decisions.
- Changing laws can also help change people's minds.
- The Convention on the Rights of Persons with Disabilities is pushing countries to change their laws. We should use the Convention to change laws that are bad for persons with intellectual disabilities.

References

- Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal Capacity*. (Paper prepared for the Law Commission of Ontario).
- Carney, T. (2012). Guardianship, "social" citizenship, & theorizing substitute decision-making law. *Sydney Law School Research Paper*, 12/25.
- Dhanda, A. (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, 429-462.
- Fiala-Butora, J. (2013). Disabling torture: The obligation to investigate ill-treatment of persons with disabilities. *Columbia Human Rights Law Review*, 45, 214-280.
- Fiala-Butora, J. (2015). Reconstructing personhood: Legal capacity of persons with disabilities. SJD Dissertation, Harvard Law School, forthcoming.

- Fiala-Butora, J., Stein, M. A., & Lord, J. E. (2014). The democratic life of the Union: Towards equal voting participation for Europeans with disabilities. *Harvard International Law Journal*, 55, 71-104.
- 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, 61–77.
- Hungarian Civil Liberties Union (HCLU) [Társaság a Szabadságjogokért, TASZ]. (2012). *Választójog és fogyatékoság* [Suffrage and Disability]. Retrieved from <http://www.youtube.com/watch?v=PBgao8ZklGY>
- Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2013). Supported decision-making: A viable alternative to guardianship? *Penn State Law Review*, 117, 1111-1157.
- Lord, J. E., & Stein, M. A. (2013). Contingent participation and coercive care: Feminist and communitarian theories of disability and legal capacity. In B. McSherry & I. Freckelton (Eds.), *Coercive care: Rights, law and policy*. Abingdon, England: Routledge.
- Mental Disability Advocacy Center (MDAC) (2013). *Legal Capacity in Europe*. Retrieved from http://mdac.info/sites/mdac.info/files/legal_capacity_in_europe.pdf
- Minkowitz, T. (2010). Abolishing mental health laws to comply with the Convention on the Rights of Persons with Disabilities. In B. McSherry & P. Weller (Eds.), *Rethinking rights based mental health laws*. Oxford, England: Hart Publishing.
- Nowak, M. (1993). *U.N. Covenant on Civil and Political Rights: CCPR Commentary*. Kehl, Germany: N.P. Engel.
- Salzman, L. (2011). Guardianship for persons with mental illness – a legal and appropriate alternative? *Saint Louis University Journal of Health Law and Policy*, 4, 279-329.
- Szegediné Dr. & Sebestyén, K. (1982). A gondnokság alá helyezés iránti perekről [About guardianship proceedings]. *Magyar Jog*, 7, 606-615.

UN General Assembly. (2007). *Convention on the Rights of Persons with Disabilities: Resolution*. Adopted by the General Assembly, 24 January 2007.

Legislation

Kiss v. Hungary, No. 38832/06 (Eur. Ct. Hum. Rts., May 20, 2010).

Plesó v. Hungary, No. 41242/08 (Eur. Ct. Hum. Rts., October 2, 2012).

Salontaji-Drobnjak v. Serbia, no. 36500/05 (Eur. Ct. Hum. Rts., October 13, 2009).

Sýkora v. the Czech Republic, No. 23419/07 (Eur. Ct. Hum. Rts., 22 November 2012).

X. v. Croatia, no 11223/04, (Eur. Ct. Hum. Rts., July 17, 2008).