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An empowering dependency: exploring support for the exercise of legal capacity

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The Convention on the Rights of People with Disabilities specifies that people with disabilities have the right to enjoy legal capacity on an equal basis with others and an accompanying duty of states parties to provide access to support for exercising legal capacity. This article uses moral philosophy to ground a discussion of personhood and supported decision-making. It discusses the cognitive prosthesis model as a possible structure for supported decision-making and identifies the potential strengths and weaknesses of such a system. In particular, it examines the effect dependency relationships will have on supported decision-making. It concludes with four principles for safeguarding the relationship of supported decision-making.

Keywords: legal capacity; personhood; supported decision-making; dependency; moral philosophy; CRPD

Introduction

Support in decision-making is an essential aspect of human interaction. We depend on the people around us to inform our individual choices on a daily basis. We decide what clothes to wear based on what others tell us the weather will be like. We make decisions about cars on the advice of mechanics. We decide what medical treatments to undergo based on the advice of doctors. We often even choose partners to spend our lives with based on the advice or reactions of our friends and family. These relationships of support in decision-making, however, can become complicated when the relationship is also one of high dependency. People with impairments that affect decision-making are often in relationships of high dependency due to both societal barriers and the nature of the impairment. The groups commonly affected by challenges in decision-making are those with cognitive disabilities, including dementia, Alzheimer's disease, learning or intellectual disability, acquired brain injury and psychosocial disabilities. Supported decision-making in these contexts presents unique issues partially because of the special accommodations required to assist the individual in the decision-making process and also because of the increased risk of domination and control.[1]

Support for decision-making is particularly important when an individual is acting as a legal agent – such as signing a contract, getting married or voting. This type of decision-making amounts to the exercise of legal capacity, which has traditionally been

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conceived of as an individualized process of decision-making. In many jurisdictions, a person with cognitive disability can have her legal capacity denied and can be restricted from making decisions in her own life, unless she can demonstrate the ability to individually use and weigh information and understand the nature and consequences of her decision. However, some people, due to impairment, environmental causes or other factors, require support for decision-making in the exercise of legal capacity. Article 12 of the recently adopted United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes a state duty to provide access to support for the exercise of legal capacity. It ensures that people with disabilities have their decisions respected by law on an equal basis with others and have access to assistance in arriving at and expressing those decisions. This has caused increased international attention on the question of how to construct supported decision-making systems[2] – both informal and formalized by law – as well as an increased need to ensure that the obligations within relationships of supported decision-making are clearly fleshed out.

The CRPD's enumeration of the right to legal capacity and the state obligation to provide access to support for the exercise of legal capacity has opened the door for a new conception of legal personhood. It respects all individuals – regardless of disability – as full persons before the law with decision-making power. It also recognizes that autonomy is exercised in relation to others and with the assistance of others. It goes beyond traditional liberal notions, which restrict personhood to individual actors operating on the basis of 'rationally' conscripted conceptions of their own 'good'. The work of Anita Silvers and Leslie Francis similarly challenges this notion and illuminates a model of trusteeship that embraces a social conception of the self. It attempts to provide a theory of justice that is inclusive of those actors who may require assistance in conceiving and expressing their own conception of the 'good'. These foundational similarities invite an examination of Silvers and Francis' model as a potential model of supported decision-making as called for in the CRPD.

The exercise of legal capacity is the tool by which an individual can reach her own conception of the 'good' through the legal validation of her will and preferences. The exercise of legal capacity affects nearly every aspect of an individual's life, from deciding where to live to accessing finances. The nature of support for the exercise of that capacity must be carefully investigated. The key challenge for the supported decision-maker is to function as an empowering dependency while maintaining neutrality to allow for the expression of the true will and preference of the individual. Silvers and Francis' prosthesis model presents us with a potential framework to achieve this. However, the role of the dependency relationship must be thoroughly considered within this prosthesis model in order to ensure that the outcome of the decision-making prosthesis is solely the will and preference of the individual. The supported decision-making relationship must also provide sufficient space for the individual to interact with, depend upon, and be influenced by the outside world to the extent desired by the individual. This space cannot fully and completely exist without the recognition of the individual as her own moral agent, with full personhood, and her own conception of the 'good'.

Increasing use of supported decision-making

The CRPD has been lauded as a revolution in human rights law for people with disabilities, but also for the wider human rights field (Quinn and Arstein-Kerslake 2012; Mégret 2008). Its drafting included an unprecedented participation of grassroots organizations (Kayess and French 2008, 4; Lord 2008; Lord 2012, 23). It integrates

social, economic, cultural and civil and political rights to a greater extent than any previous human rights instrument (Lord and Stein 2009, 259). Its monitoring mechanisms are arguably the strongest we have seen in international human rights, requiring the establishment of monitoring bodies both inside and independent of the government (Lord, Suozzi, and Taylor 2010, 570; Stein and Lord 2010). Although it does not espouse any new rights (Arbour 2006), it is the first binding international human rights instrument to address the rights of people with disabilities (Weller 2009, 83).

One of the most contentious as well as ground-breaking articles in the CRPD is Article 12 on the right to 'equal recognition before the law' for people with disabilities (Dhanda 2006–2007, 438–456). The first three paragraphs of the Article are, as follows (CRPD 2007):

Article 12

Equal recognition before the law

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.

We have seen the right to equal recognition before the law in other human rights instruments (UDHR 1948; ICCPR 1967; CEDAW 1980), but it has never been fleshed out in the manner that the CRPD does. The text of Article 12 includes not only the general right to equal recognition before the law but also enumerates what rights are essential for the realization of that recognition. It guarantees the rights to legal capacity as well as support in exercising that legal capacity.

Article 12 has spurred much academic and political discussion since the adoption of the CRPD in 2006. The United Nations monitoring body for the CRPD, the CRPD Committee, has stated that supported decision-making systems must *replace* systems of substituted decision-making (CRPD 2011a, 2011b, 2014) – however, there remains much confusion on what those terms mean. Fortunately, the academic world as well as non-governmental organizations have conducted lively and powerful discussions on the topic. The products of those discussions have helped establish the foundation of the rights as well as the key areas that States Parties to the Convention must act.

Before outlining the requirements of Article 12, it is necessary to clarify what is meant by 'legal capacity' and how it affects the lives of individuals. Legal capacity has two components. The first is the capacity to hold rights. This is a recognition of the individual as a subject under the law who has rights and privileges, as well as obligations. The second component is the capacity to act. This is the ability to legally engage with other subjects under the law; to create, maintain and extinguish legal relationships, and to enforce rights before the appropriate authority (OHCHR 2005). Legal capacity allows an individual to enter into contracts, to marry, to vote, to have decisions respected by the law, etc. In this way, legal capacity is the law's recognition of an individual as a decision-maker and moral agent – it is the granting of personhood to the individual – it is 'considerability' given to the individual via a legal construct (Arstein-Kerslake and Flynn 2014).

According to liberal accounts of justice, an individual is only granted 'considerability' if they are perceived to have a 'conception of the good' (Silvers and Francis 2007, 311). There is not room in this article to explore the deeper meaning of a 'conception of the good' or whether it can ever be accurately determined if someone does or does not possess it. However, it is very difficult to discover one's own conception of the good, let alone express it, if that individual's own will and preferences are not respected in law. How can someone be expected to explore her conception of the good when she is not given the space to direct her own life? Therefore, 'considerability' and the recognition of legal capacity – respect for an individual's will and preference – are intimately tied to each other. Furthermore, it may not be the law's role to make a determination that an individual cannot conceive of her own 'good'. Society may be better served if the law assumes that everyone can conceive of her own 'good'. The state's role, then, would be to protect all individuals' right to 'considerability'. It would strive to enable all individuals to express their wills and preferences in order for them to reach their own conception of the 'good'.

Currently, there are legal mechanisms for removing legal capacity from individuals. This is done in a variety of ways (Dhanda 2006–2007, 431–433), but one of the clearest examples is substituted decision-making mechanisms such as guardianship. Under these systems, an individual can be deemed to lack the decision-making skills necessary to exercise her own legal capacity. The state then removes legal capacity from the individual and vests it elsewhere, sometimes in the court or in an appointed guardian. Through this removal of legal capacity, the individual is essentially deemed a non-person under the law. It is a kind of civil-death (Quinn and Arstein-Kerslake 2012). The individual is no longer a legal actor, can neither enter into legal relationships nor be held responsible for her actions in the same way that an individual with legal capacity can be. While these systems profess to be created in the interests of protecting people, the result is quite the opposite in many ways (Winick 1995). Without legal capacity, the individual is left stripped of the tools necessary to protect herself. She is left disempowered by the law's denial of her personhood and has become an object to be managed by other legal processes and outside actors. She is no longer an individual whose decisions will be respected – she is treated as not possessing a valid will or preference for the direction of her life or decisions related to it.[3] Furthermore, in many cases, she actually lacks the right to contract with an attorney in order to protect her own rights and interests before the law. Therefore, in denying legal capacity, the individual is left vulnerable to external forces. Not only are the rights of the individual being violated by the denial of capacity itself, but once denied, the individual is then left open to a variety of other rights violations because she has lost the legal means to protect herself.

This is not to say that the solution is a preference for autonomy above all other rights and needs of the individual. The right to legal capacity does not call for a neo-liberal removal of all state-sponsored assistance for people that need support in decision-making. Article 12 asks for quite the opposite. The text of the article includes both the right to legal capacity and the state obligation to provide access to support in exercising legal capacity. It asks for a system where an individual is not denied legal capacity, but provided with the means to exercise that legal capacity. None of us exercise legal capacity alone or in a vacuum. We take support from all around us – our friends, families, experts and professionals. We are continually influenced by outside sources. Due to a combination of societal barriers and limitations resulting from impairment, people with cognitive disability may not be able to exercise their legal capacity without specific

support. Article 12 establishes that the state has an obligation to ensure that everyone has meaningful access to that support.

The reality is that some people with cognitive disability may always be dependent on others for the support necessary to make decisions and exercise legal capacity. The goal of the support paradigm established in Article 12 is to ensure that support is provided, but people with cognitive disability are not forced to be debilitatingly dependent on others for decision-making on their behalf. The paradigm aims to simultaneously empower individual autonomy and to embrace engagement with others and the community in a way that informs decision-making and fosters inclusion and social cohesion.

Exploring supported decision-making

'*Considerability*' *of persons with cognitive disability*

As is a goal of the CRPD, an individual using support for decision-making must be perceived as a subject within the relationship and *not* an object (Quinn and Degener 2002, 14). This means that the individual with a cognitive disability must not be thought of as an object of charity that the support person is assisting out of the goodness of her heart. This type of relationship creates an unequal power balance between the individuals that does not permit the appropriate space for the individual using the support to exercise her decision-making skills and express her true will and preferences. It also stifles the support person's ability to cast aside preconceived notions of the individual and the disability and see the core of the individual and the will and preferences that she desires to express.

In order to avoid this objectification of the individual, the individual must be respected as a moral agent with full legal personhood – as is the goal of Article 12 in its requirement that people with disabilities be given equal recognition under the law (Arstein-Kerslake and Flynn 2014). Much has been written on how people with cognitive disabilities fit into moral philosophy and whether they can be granted full 'personhood' – or 'considerability' – in theories of justice (Kittay and Carlson 2010). Some argue that they do not fit into much relied upon theories, such as Rawlsian social contract theory (Nussbaum 2009, 331–332; Singer 2009). The concern is that the requirement of cognition and the ability to engage in contemplation and communication of the 'good' excludes people with cognitive disabilities who are perceived as not being able to fulfil these requirements for personhood (Silvers and Francis 2005, 49; Singer 1994; Baroff 2000). This exclusion relegates people with cognitive disabilities into a category of beings that are the object of charity and are not held responsible for the same obligations as those who possess personhood.

Several solutions have been presented to attempt to place people with cognitive disabilities back into theories of justice. Wong (2010) has suggested that it is simply more morally dangerous to exclude people with cognitive disabilities than it is to include them. Silvers and Francis have departed from Rawl's belief that only people who are viewed as reciprocators of benefit can be included as participants in the social contract (2009, 489). They have suggested that the problem with social contract theory lies in its emphasis on the bargaining paradigm. They conclude that we must move away from thinking that the only true participant in social contract theory is one with the ability to bargain – to reciprocate benefit and negotiate that benefit in a competitive manner. Instead, they assert that the social contract can be operated on a paradigm of trust – doing justice towards others because of an intrinsic trust in ourselves and a trust that others will act similarly justly towards us. Silvers and Francis say that all people, even particularly vulnerable

groups such as those with cognitive disability, can be included in social contract theory if we are all empowered to trust each other and our interactions – thereby creating room for participants in the social contract that may not be competitive bargaining actors (2005, 41 and 75). Separately, they argue that forming conceptions of the good – a requirement of personhood for theories such as Rawls' – does not need to be restricted to the individual alone. They claim that it is always 'socially scripted and interactively developed' for people with and without disabilities, and a recognition of this allows us to expand the definition of how people form and express their own 'good,' thereby allowing us to expand the notion of who is included in the category of 'person'. Furthermore, Silvers and Francis assert that although people with cognitive disabilities may need assistance, they do – as everyone does – have individualized and subjective accounts of the 'good' (2009, 485).

Nussbaum has similarly criticized social contract theory and instead advocates for Sen's Capabilities Approach, in which a theory of justice is based on each individual's 'capabilities' – defined as opportunities for achievement (Sen 1999). Unlike Sen, who has avoided the specific enumeration of capabilities, Nussbaum has created a list of 10 central capabilities that she believes are essential for a life of human dignity – including the capability of 'practical reasoning' or 'being able to form a conception of the good and to engage in critical reflection about the planning of one's life' (2006, 76–78). Without a certain threshold of these capabilities, Nussbaum says that justice is not being met. The theory is meant to be inclusive of people with cognitive disabilities and importantly asserts that capabilities should be enabled on an equal basis for those with and without disability. However, Silvers and Francis have raised the issue that Nussbaum's approach presents a problem for people with cognitive disability who are not able to meet certain capability thresholds, such as 'practical reasoning' (2009, 484). Nussbaum labels this 'unfortunate' and says that in these cases, we must do all that is possible to attempt to bring the individual's functioning up to the threshold level that is set for other citizens (2006, 192). Silvers and Francis assert that this is incorrect, instead we should be working to bring people with disabilities to the 'capabilities' included in their *own* personalized conception of the good (2009, 484).

Following the tenants of human rights law, people with disabilities must be participants in theories of justice and must receive equal benefit and protection of the laws. This can be found in the concept of universality of rights that is reiterated in several different human rights instruments (UDHR, ICCPR) and stated in the first paragraph of the preamble of the CRPD:

> Recalling the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world.

This remains true in the realization of the right to equal recognition before the law and its mandate for access to support for the exercise of legal capacity. Therefore, people with cognitive disability participating in relationships of supported decision-making must be accorded full personhood and their individual conceptions of the 'good' must be respected – no matter whether or not there is any empirical indication of complex moral contemplation emanating from the individual. Without this 'considerability,' the relationship will be defunct – it will be merely another service provided to the disabled, another piece of charity – objectifying the individual and ultimately fostering vulnerability and marginalization.

The prosthesis model

To allow for the inclusion of people with disabilities in theories of justice, philosophers Silvers and Francis have outlined a model that envisions the support person as a type of cognitive prosthesis. Previously, an individual would have been thought of as not being included as a 'person' for the purposes of constructing a theory of justice if the individual was not perceived to be able to independently construct his or her own conception of the 'good' (2007, 326). Silvers and Francis have conceptualized this trusteeship theory in an effort to outline how 'considerability' can include persons with cognitive disability via the collaborative construction of personalized theories of the good for and with people with cognitive disabilities (2009, 485). The prosthesis model may be useful to examine for constructing systems of supported decision-making that will replace those of substituted decision-making.

Silvers and Francis argue that people with cognitive disabilities *do* have personalized accounts of the good and trustees can be used as cognitive prostheses to allow those conceptions of the 'good' to be expressed, thereby allowing the individual with cognitive disability entrance into theories of justice as *full participants*. This trustee would not act on the basis of stepping into the role of the individual – it would instead act as merely a tool for the expression of the individual's personalized conception of the 'good':

> as a prosthetic arm or leg executes some of the functions of a missing fleshy one without being confused with or supplanting the usual fleshy limb, so, we propose, a trustee's reasoning and communication can execute part or all of a subjects own thinking processes without substituting the trustee's own idea as if it were the subject's own. (2009, 485)

Like other prosthetics, the trustee must be responsive to the individual's motivations and not vice versa. The products of the relationship should be attributed to the individual and not to the trustee – as a prosthetic leg, although essential for running a race, is not awarded for the races that its owner wins (2009, 486).

Using a prosthesis model for cognition does raise some concerns. The first is the ableist implications inherent in the term 'prosthetic'. A prosthetic is often used to make an addition to a body to make it fit into societal notions of bodily 'normalcy'. This can perpetuate dangerous conceptions of disability as a phenomenon that needs correction. It also ignores the lived experiences of disability, which may or may not include the desire for a prosthetic (Loja et al. 2014; Overboe 1999). This is particularly concerning when applied to cognition. Cognition is a key part of what makes a person a unique individual. There should not be a standard of cognition that is upheld as the most desirable – that would be a fiercely ableist notion. Assistance with a cognitive process, such as decision-making, must include a recognition that every mind operates differently and deserves an equal amount of respect. This recognition will obviate the need for any 'correction' of cognitive processes because there is nothing to correct if it is accepted that every mind is whole and complete within itself.

The mind is a unique organ. It is what distinguishes us as humans – our mind is what makes us who we are, it contains our personality, our desires and our prejudices. These are things that it would be impossible for a supporter to erase in order to act as a mechanical prosthesis for the thought processes of another individual. However, the uniqueness of our minds is also part of what makes someone a good supporter. The supporter should use her whole self to build a trusting and reciprocal relationship with the individual using the support. At the same time, the supporter must not unduly influence

the decision of the individual, but empower the individual to make and communicate her own decisions.

According to Silvers and Francis, the product of the relationship between the trustee and the individual should be free of the personality and preferences of the trustee. It should 'reveal the personhood' of the individual through assistive thinking that takes the individual as an end within herself, not a means to something else desired by the trustee. The trustee must also divorce his or her identity from the process of assistive cognition as well as the product of that process. This places significant demands on the trustee to engage qualities of thoughtfulness and insight to ensure that the individual's conception of the good is not being conflated with that of the trustee's own biases and preferences. Additionally, a trustee has an obligation to be perceptive enough to understand what the individual needs in order to flourish and then to carry out those needs to the greatest degree possible. Most importantly, Silvers and Francis emphasize that a trustee is not a *representative* for an individual with cognitive disability. A trustee's role is restricted to enabling the individual to 'configure ideas so as to represent themselves while the process unfolds through their use, via prosthetic functioning, of the trustees' cognitive and linguistic skills' (2009, 493).

Silvers and Francis have specifically stated that their prosthesis trustee model is not meant to create a surrogacy approach where trustees can substitute their decision-making for that of the individual using the support (2009, 485). Article 12 similarly demands the elimination of substituted decision-making systems such as guardianship and conservatorship in which the individual's legal capacity to act is assigned to a representative who will make decisions in the 'best interests' of the individual as opposed to in accordance with the individual's own will and preference (their personalized conception of the good) (CRPD 2011a, 2011b, 2014). The elimination of substituted decision-making elicits the question of what action to take in the 'hard cases' where an individual is not expressing a will and preference. Article 12(3) dictates that any action taken always respects the 'rights, will and preference' of the individual. Therefore, in situations where the individual's will and preference cannot be ascertained, a representative may make decisions on behalf of the individual that are in line with what that individual's imagined will and preferences are based on all available evidence.

If the prosthesis trustee model is to take the place of substituted decision-making models, it must also address these situations in which individuals are unable to express their will and preference and another person is needed to interpret the imagined will and preferences of that individual. Silvers and Francis have specifically stated that the trustee is only supposed to enable the individual to formulate her own ideas through the prosthetic cognitive and linguistic skills of the trustee. While this largely fits in with the paradigm of Article 12, it does not address these hard cases. Silvers and Francis tackle this apparent gap in the prosthesis theory with the assertion that subjective theories of the 'good' (the will and preference of the individual) can be constructed 'by, with, and for' dependent agents (2007, 334) – presumably allowing for a representative to imagine the will and preference of the individual, where the individual is unable to communicate them herself. Keeping in mind that this means the individual's *own* conception of the good and her *own* will and preference – acknowledging that people with disabilities must not be discriminatorily subject to best interests judgements being imposed on them, and are instead owed particular attention to ensure that the individual's personalized construction of their own good over-rides all outside notions. In this way, the prosthesis theory creates a deeper understanding of individual accounts of the 'good' by relying on a kind of

'dependent agency' for the creation and expression of the individual's will and preference.

A supported decision-making system that is compliant with Article 12 CRPD must be absolutely clear that it does *not* buy into the false notion that some individuals need to be brought up to a level of perceived 'normalcy' to fulfil the requirements for 'considerability'. All individuals in a supported decision-making system must be granted considerability from the starting point on the belief that, being born human, every individual has a conception of the good – although not every individual is able to formulate and express that good on their own. The role of a support person, or a trustee prosthesis, must be limited to assistance with the expression and further formulation of the individual's assumed to be already existing conception of the good. The trustee prosthesis can interpret the ideas of the individual in situations where the individual has unique communication methods that are not easily recognizable to those around the individual. The support person may also provide assistance where the individual needs help in formulating her ideas and expressing them in a way that allows others to respect and carry out those wishes.

In some cases, it may be an exercise of faith to accept that an individual has a conception of the good because there may be no obvious outward expressions of that 'good' – however, the only evidence that one should need to accept that another has a conception of the good is that the individual is a fellow human being. Some would argue that this is specie-ism (Singer 2009), and maybe it is. But giving recognition to all humans as 'persons' with considerability is essential if equality before the law is going to be reached.

Dependency relationships

> Inequality of power is compatible with both justice and caring, if the relation does not become a relation of domination. (Eva Feder Kittay 1999, 34)

The product of a relationship of supported decision-making should be the exclusive expression of the individual's will and preference. Similar to a prosthesis, the individual must have control over the relationship and the end result should be a 'mechanized' expression of the individual's decision. However, when the prosthesis has a mind of its own, the relationship to reach the end result looks much different than with a truly mechanical prosthesis. The term 'prosthesis' has the potential to present a false picture of the relationship between the two individuals in a supported decision-making relationship. A prosthesis, in the conventional sense of the term, does not have its own mind, will or preferences. It is an object that its user can manipulate, but cannot manipulate its user. A supported decision-maker, however, is an individual with her own biases, judgements and the ability to manipulate – intentionally and unintentionally. The goal of the supported decision-maker is to do everything in her power to not impose her own will and preferences on the individual whom she is supporting. This is made increasingly complicated in a relationship of dependency where the dependent individual may be accustomed to deferring to others and may be vulnerable to manipulation because she is worried that she risks losing her support person if she disagrees with her. The supported decision-making relationship, then, must be an empowering dependency that produces prosthetic-like results free of undue bias and influence.

The support paradigm in Article 12 of the CRPD intends to provide tools to individuals with cognitive disability to reduce levels of dependency. This should open up space for the individual to explore her own conception of the good – her own will and preference – without an oppressive burden of dependency weighing down on her. In dependency relationships, the power imbalance has the potential to leave the supporter relatively unchecked, making room for the supporter to intentionally or unintentionally influence the individual's decisions in an inappropriate manner. However, as Kittay identifies, dependency relationships are a key aspect of our society and we are free to engage in them. We are all in dependent relationships – some destructive and others deeply nourishing. We have the right to engage in these relationships. Some people allow their mothers to be influential in their decision-making throughout their adulthood. Others depend on their partners for all decision-making, from daily grocery shopping to major financial expenditures. Others have mentors, friends and colleagues whose advice they follow largely blindly, having faith in the other individual and in the relationship that they have with that individual. These dependency relationships are not unique to disability – they permeate our social networks. In a relationship of supported decision-making or cognitive prosthesis – dependency does not need to be eliminated. It only needs to be monitored to ensure that it is empowering the individual to exercise choice – even when that choice is to engage in heavily dependent relationships. The key is to safeguard that choice – to ensure that the choice to be in the relationship of decision-making dependency lies in the individual and not in the supporter.

The state's role in regulating supported decision-making

Kittay examines dependency relationships as a key aspect of equality – calling for a theory of justice that does not ignore the important role dependency relationships play in the lives of citizens, and particularly women. She asserts that no theory of justice can be complete without a thorough consideration of dependency relationships. Equality will never be achieved if the care work of women with dependents is not fully accounted for (1999, 37–38).

In examining the dependency relationship, Kittay observes that a just system must both empower the support person and strive to decrease the level of dependency that the individual has on the support (1999, 37). This is particularly important in the context of supported decision-making. Kittay calls for the provision of outside assistance to the 'care worker' to allow her to better provide the support to the individual who is 'dependent' on her and to allow her the freedom to engage in activities outside the dependency relationship. This recognizes that both individuals in a dependency relationship have specific needs that must be met – both inside and outside the relationship.

In a system of supported decision-making, there must be a similar holistic consideration of the dependency relationships in the individual's life and particularly within the relationship of supported decision-making. Additionally, as Kittay highlights, the needs of both the individual and the supported decision-maker must be taken into account. In many cases, it is extremely difficult to determine whether a particular dependency relationship is healthy or harmful. In these cases, it is similarly hard to determine what the state's role should be – where it should be allowed to intervene, where its obligations lie, and what level of support should be provided for the individuals.

Case study. Joe, a man with high support needs, lives with his father.[4] Joe and his father have a well-established life in a flat together. Joe has a set routine of activities he enjoys every day and his father has a full-time job. Joe depends heavily on his father for

day-to-day living. His father provides the meals, arranges Joe's activities during the day and helps Joe with personal care needs. Those close to Joe and his father have noticed that his father heavily influences Joe's decisions and sometimes acts quite paternalistically towards Joe. Others have also noticed that Joe's father seems often exasperated and becomes frustrated with Joe frequently. They receive support from time to time from a local residential centre ('the centre'), where Joe sometimes stays overnight for short periods of time. One week, Joe's father fell temporarily ill and Joe went to stay at the residential centre. When his father was well again and was ready to have Joe back home, Joe expressed the desire to go home, but the centre did not agree. The centre felt that the relationship between Joe and his father had become one of unhealthy dependence. The law in the jurisdiction allowed the residential centre to determine that Joe lacked capacity to make his own decisions regarding where he lives because of the heavy influence that his father has over him. They decided, instead, that it was in Joe's 'best interest' to remain at the residential centre, where they would allow supervised visits with his father. After this, Joe's behaviour got increasingly difficult and he repeatedly expressed his wishes to return home. On more than one occasion, he also attempted to leave the residential centre and return to the flat he shared with his father.

International human rights law and the support paradigm requires a response from the state that respects Joe's right to legal capacity and provides him with access to meaningful support for the exercise of that capacity. There are two very important points to consider in examining the dictates of human rights in such a case. The first, which is informed by Silvers and Francis' prosthesis model, is that where an individual requires support in decision-making, the product of that support must emanate from the will and preference of the individual (2007, 328). The second, informed by Kittay's work, is the role of dependency in this father and son relationship and what could have been done differently to foster the development of an 'empowering dependency'.

In order to meaningfully uphold the right to legal capacity to act, the state must protect *choice*. Therefore, the state has an obligation to ensure that an individual is free to make choices and to have those choices enforced and respected by the law – this includes ensuring that *real* choice is available to the individual, which means choice from a variety of options and choice that is truly from the individual. For example, the state must provide support to ensure that an individual is actually making a *choice* to allow another individual to have a significant amount of control over their life. This is where the right to supported decision-making is essential. To comply with Article 12 of the CRPD, the state must not only refrain from interference with an individual's right to exercise legal capacity – the state must also provide the support necessary for the individual to exercise her legal capacity – this includes support to ensure that the individual is free to make her own choices and that she has a meaningful set of options to choose from.

In the case of Joe and his father, the state would have a role in ensuring the son had the support necessary to make him aware that he had meaningful options for living outside his father's home. However, if he ultimately chose to remain in his father's home, under his father's control, that decision must be respected. A choice is only a meaningful choice if there are real and tangible alternatives to choose from. It was a violation of the son's right to legal capacity to remove his ability to choose to engage in the relationship. Instead, the state's role in this situation should have been to provide meaningful options for people with cognitive disability, like the son, to receive support to live independently of their families. The state must also ensure that people with cognitive disability have information about different living options that is accessible. This may mean the provision

of easy-to-read information, access to the physical buildings where the information is provided and/or the development of relationships of trust with people that are able to give the individual information regarding these options. It does *not* mean that the state – exercising its power through the residential centre in Joe's case – is permitted to intervene and remove decision-making power from the individual and impose its own decision of what is best for the individual.

The dependency dynamic must also be considered in ensuring that choice exists and is protected. If, as the prosthesis model tells us is essential, the son's decision-making is not reflective of his or her true will and preferences, due to the undue influence of his father, then according to the human rights norms established in the CRPD, the state's role is still *not* to remove decision-making power. The state's role instead, is to strive to provide the support necessary to allow a healthy support in decision-making to occur. This may be through the son's relationship with his father, or may require outside assistance from a third party. However, due to the well-recognized importance of familial relationships, it is likely that the best option here is to strive to facilitate the father–son relationship to include healthy support in decision-making.

This is where Kittay's analysis of the importance of dependency relationships is relevant. She recognizes that a society must consider the needs of the 'care-worker' or support person – which are substantial – in order to create a just society. Here, a system of supported decision-making should provide support to the son to be empowered to meet his own needs and make his own decisions to the extent desired. But, if the son desires, it may also include a considerable amount of assistance for the father in order for him to become the kind of prosthesis support that his son has a right to. This may include addressing why the father developed a seemingly overly-intrusive relationship with his son, which could be done through counselling, contact with other parents in similar situations or other assistance. It would also be important to provide training and information to the father on how to be a support for his son in the decision-making process without inserting his own preferences – training on how to be more like a 'cognitive prosthesis'.

The development of this type of support paradigm will require dedicated resources from the state. However, it seems that personhood and core human rights should be a priority in allocating state resources. Furthermore, in many jurisdictions, there is a significant amount of funding currently going into many institutional and choice-denying programmes directed at people with disabilities. If those programmes were re-evaluated in light of the CRPD, it is likely that the funding could be redirected towards support systems which respect the personhood and agency of the individual. The following section provides principles for the development of such systems.

Four principles for safeguarding the relationship of supported decision-making

(1) Ensure that both parties are *respected as moral agents* with full personhood – including legal personhood, which entails the recognition of the individual's legal capacity.
(2) Ensure that the inequality of power or dependency that exists is not abused and does not turn in to *domination*.
(3) Ensure that the product of the relationship is always an *expression of the individual's own will and preference* and not that of the supporter.
(4) Ensure that any system of supported decision-making does *not over-regulate* the lives of individuals with cognitive disabilities.

Both parties in a supported decision-making relationship must be recognized as moral agents free from the derogation of their right to legal capacity. The balance of power between the parties cannot be maintained under the stress of the psychological disempowerment that occurs as a result of denials of legal capacity and the resulting exclusion from society.

In order to prevent the support person from dominating the relationship, both the individual using support and the support person must have adequate access to resources to provide assistance when needed. For example, access to information about what a supported decision-making relationship should look like and access to others to turn to for advice. There must also be a mechanism for the individual using the support to meaningfully challenge their supporter and/or the ability to get a different support person. This may be a government office or a non-governmental organization that is provided the resources to provide this role.[5]

If the relationship does enter into domination, then the product of the relationship will not be the true will and preference of the individual. To minimize this possibility, the individual must be present and participating in all decision-making processes and interactions with third parties, where desired by the individual. This will allow the individual to better monitor the support person and to express her own will and preference when she desires. Training and education on the nature of supported decision-making will also be important including training to empower the individual to feel confident to express her will and preference. Both parties must have the tools necessary to understand and take action when the relationship is not producing the expression of the individual's will and preference.

These safeguards must exist without undue intrusion into the lives of people with cognitive disability – whom are often subject to high levels of regulation, particularly in comparison to those without cognitive disability. There is not room in this article to fully explore the history behind the over-regulation of the lives of people with disability and its effect. However, it is essential to keep this in mind when developing any system of supported decision-making. Decision-making permeates every aspect of our lives and therefore, the state must be very careful to provide protection for choice through safeguarding from the undue intrusion of the state and others into the lives of people with disability. This is admittedly a significant challenge, but one that is essential to meet because failing to protect individuals from undue intrusion by the state essentially negates any protection provided from the undue intrusion of others. In order to truly protect choice for people with disability, it must be done holistically, and the state must be restrained from intruding into the lives of people with disability just as other actors are. This will mean giving the individual the power to control what resources to use as safeguards wherever possible.

Conclusion

In light of a new understanding of our interdependence as reflected in the CRPD, as well as a general desire to create a more just and inclusive society, the need to fully explore the supported decision-making relationship is particularly pertinent. Silvers and Francis' prosthesis model is useful in its inclusion of people with cognitive disabilities into theories of justice. It is also useful in its examination of the relationship of support in decision-making and conceptualizing the individualized 'good' life. Its goal of a nearly mechanical support process that produces only the emanation of the will and preference of the individual is important, but may ignore the reality of human interaction and

influence. While the product of any supported decision-making relationship should be the will and preference of the individual, that process will always include influence and sharing between two people. The term 'prosthesis' may not be able to fully encompass the reality of this interactive relationship. This is a problem because the relationship must be acknowledged as one of influence and interaction in order to put in place the essential safeguards to ensure genuine choice for the individual and realization of her will and preferences.

A relationship between a supported decision-maker and a person using support is unique – it must be characterized by *empowering* dependency, with obligations and respect on both sides of the relationship. This entails a conceptualization of autonomy in which autonomy is *created* by, and intricately tied to, dependency. The four principles outlined in this article aim to provide a road map for policy-makers, legislators and others to create systems that foster supported decision-making relationships that protect autonomy and provide freedom from abuse and ill-treatment.

Notes

1. Much of the increased risk of domination and control is due to the lack of sufficient supports in the community to enable people with cognitive disabilities to be free from dependence on familial caregivers and/or institutional settings.
2. Momentum for law reform and pilot projects on supported decision-making has begun in several regions: Ireland [see Assisted Decision-Making (Capacity) Bill 2013, no. 83 of 2013, Sponsored by Minister for Justice and Equality, presented 15 July 2013]; Australia [see Margaret Wallace, 'Evaluation of the Supported Decision-Making Project, Office of the Public Advocate', Muirgen Nominees Pty Ltd Consulting Services (November 2012)] and the European Union [see 'Who Gets to Decide?: Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities', Council of Europe, Commissioner for Human Rights, CommDH/IssuePaper(2012) 2, (20 February 2012)] among others.
3. Some legal capacity systems, such as partial guardianship, only deny the individual's legal capacity in certain areas of her life. While this is an improvement on systems that wholly deny legal capacity to individuals (plenary guardianship), the denial of legal capacity, even in the smallest way, is still a form of denial of the individual as a legal actor. The individual is not being treated as a 'person' who has a will and preference that she has a right to express and have validated.
4. This is a fictional set of facts.
5. For an example of support arrangements codified in legislation, see The Representation Agreement Act (British Columbia) [RSBC 1996] Ch. 405.

References

Arbour, Louise. 2006. UN High Commissioner for Human Rights, "Statement on the Ad Hoc Committee's Adoption of the International Convention on the Rights of Persons with Disabilities New York." General Assembly Ad Hoc Committee, 8th session, New York, 5 December.

Arstein-Kerslake, Anna, and Eilionoir Flynn. 2014. "Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity." *International Journal of Law in Context* 10 (1): 81–104.

Baroff, George S. 2000. "Eugenics, "Baby Doe," and Peter Singer: Toward a More "Perfect" Society." *Mental Retardation* 38 (1): 73–77. doi:10.1352/0047-6765(2000)038<0073:EBDAPS>2.0.CO;2.

CEDAW (Convention on the Elimination of Discrimination against Women). 1980. GA res. 34/180, 34 UN GAOR Supp. (No. 46) at 193, UN Doc. A/34/46; 1249 UNTS 13; 19 ILM 33.

CRPD (Committee on the Rights of Persons with Disabilities). 2011a. Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Tunisia, Committee on the Rights of Persons with Disabilities (CRPD), 5th Sess., at 4, UN Doc CRPD/C/TUN/CO/1, April 11–15.

CRPD (Committee on the Rights of Persons with Disabilities). 2011b. Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Spain, Committee on the Rights of Persons with Disabilities (CRPD), 6th Sess., at 5, UN Doc CRPD/C/ESP/CO/1, September 19–23.

CRPD (Convention on the Rights of Persons with Disabilities). 2007. G.A. Res. 61/106, U.N. Doc. A/61/611, 3 U.N.T.S. 2515.

CRPD (Committee on the Rights of Persons with Disabilities). 2014. General Comment No. 1, Article 12: Equal Recognition Before the Law, Committee on the Rights of Persons with Disabilities, 11th Sess., at 26–29, UN Doc. No. CRPD/C/GC/1, March 31–April 11.

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: 429–462.

ICCPR (International Covenant on Civil and Political Rights). 1967. GA res. 2200A (XXI), 21 UN GAOR Supp. (No. 16) at 52, UN Doc. A/6316 (1966); 999 UNTS 171; 6 ILM 368.

Kayess, Rosemary, and Phillip French. 2008. "Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities." *Human Rights Law Review* 8: 1–34. doi:10.1093/hrlr/ngm044.

Kittay, E. F., and L. Carlson, eds. 2010. *Cognitive Disability and Its Challenge to Moral Philosophy*. Chichester: Wiley-Blackwell.

Kittay, Eva Feder. 1999. *Love's Labor: Essays on Women, Equality and Dependency*. New York: Routledge.

Loja, Ema, Maria Emília Costa, Bill Hughes, and Isabel Menezes. 2014. "Disability, Embodiment and Ableism: Stories of Resistance." *Disability & Society* 28 (2): 190–203. doi:10.1080/09687599.2012.705057.

Lord, J. 2008. "Forging an International Advocacy Net-work on Disability Rights." In *New "Rights" on the Rise*, edited by C. Bob. Philadelphia: University of Pennsylvania.

Lord, J. 2012. "The U.N. Disability Convention: Creating Opportunities for Participation." *Disability and the Law, Business Law Today*, 23–28.

Lord, Janet E., and Michael Ashley Stein. 2009. "Social Rights and the Relational Value of the Rights to Participate in Sport, Recreation, and Play." *Boston University International Law Journal* 27: 249–281.

Lord, Janet E., David Suozzi, and Allyn L. Taylor. 2010. "Lessons from the Experience of U.N. Convention on the Rights of Persons with Disabilities: Addressing the Democratic Deficit in Global Health Governance." *The Journal of Law, Medicine & Ethics* 38 (3): 564–579. doi:10.1111/j.1748-720X.2010.00512.x.

Mégret, Frédéric. 2008. "The Disabilities Convention: Towards a Holistic Concept of Rights." *The International Journal of Human Rights* 12 (2): 261–278. doi:10.1080/13642980801954363.

Nussbaum, Martha. 2006. *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge, MA: Harvard University Press.

Nussbaum, Martha. 2009. "The Capabilities of People with Cognitive Disability." *Metaphilosophy* 40 (3–4): 331–351. doi:10.1111/j.1467-9973.2009.01606.x.

OHCHR (Office of the United Nations High Commissioner of Human Rights). 2005. '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.

Overboe, James. 1999. "'Difference in Itself:' Validating Disabled People's Lived Experiences." *Body & Society* 5 (4): 17–29. doi:10.1177/1357034X99005004002.

Quinn, G., and A. Arstein-Kerslake. 2012. "Restoring the 'Human' in 'Human Rights': Personhood and Doctrinal Innovation in the UN Disability Convention." In *The Cambridge Companion to Human Rights Law*, edited by C. Gearty and C. Douzinas, 36–55. Cambridge: Cambridge University Press.

Quinn, Gerard, and Theresia Degener. 2002. "The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability." United Nations, doc. no. HR/PUB/02/1.

Sen, Amartya. 1999. *Development as Freedom*. New York: Knopf.

Silvers, Anita, and Leslie Pickering Francis. 2005. "Justice through Trust: Disability and the "Outlier Problem" in Social Contract Theory." *Ethics* 116 (1): 40–76. doi:10.1086/454368.

Silvers, Anita, and Leslie Pickering Francis. 2007. "Liberalism and Individually Scripted Ideas of the Good: Meeting the Challenge of Dependent Agency." *Social Theory and Practice* 33 (2): 311–334. doi:10.5840/soctheorpract200733229.

Silvers, Anita, and Leslie Pickering Francis. 2009. "Thinking about the Good: Reconfiguring Liberal Metaphysics (or not) for People with Cognitive Disabilities." *Metaphilosophy* 40 (3–4): 465–498.

Singer, Peter. 1994. *Rethinking Life and Death*. New York: St. Martin's Press.

Singer, Peter. 2009. "Speciesism and Moral Status." *Metaphilosophy* 40: 567–581. doi:10.1111/j.1467-9973.2009.01608.x.

Stein, M., and J. Lord. 2010. "Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities, and Future Potential." *Human Rights Quarterly* 32 (3): 689–728. doi:10.1353/hrq.2010.0003.

UDHR (Universal Declaration of Human Rights). 1948. GA res. 217A (III), UN Doc A/810 at 71.

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.

Winick, Bruce J. 1995. "The Side Effects of Incompetency Labeling and the Implications for Mental Health." *Psychology, Public Policy and Law* 1 (1): 6–42. doi:10.1037/1076-8971.1.1.6.

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.