

State Intervention in the Lives of People with Disabilities: The Case for a Disability Neutral Framework

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Abstract

People with disabilities continue to experience a disproportionately high level of state intervention in their private lives. Many disabled people's organisations have long sought to challenge this discriminatory approach, and in recent times, have relied upon the provisions of the UN Convention on the Rights of Persons with Disabilities in support of their claims. In this article, we argue for the abolition of disability-specific legal bases for state intervention in the private lives of adults. We also argue for the introduction of a narrower disability-neutral legislative framework for state intervention in the lives of all adults – based on risk of imminent and serious harm to the individual's life, health or safety; while providing greater respect for the person's legal capacity as expressed through her will and preferences.

Introduction

Political thinkers from Ancient Greece to contemporary republican theorists have considered in depth the complexity of the boundaries between individual freedom and state intervention.¹ The criteria for delineating the legitimacy of state intervention in the affairs of individual citizens has varied considerably throughout the centuries,

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¹ For further reading on the boundaries between individual freedom and state intervention see for example Neu (1971); Mulgan (1987); Rousseau (2003); Rawls (2009); Pettit(1997).

with legal regulation of this arena reflecting changing cultural, social and moral norms in various political communities.

People with disabilities continue to experience a disproportionately high level of state intervention in their private lives (Barton 1993). ‘State intervention’ in this article refers to unwanted state involvement in the lives of adults. Often, this intervention arises as a result of the support that people with disabilities seek from the state to enable them to participate in society on an equal basis with others. In other words, people with disabilities are asked to pay a high price for accepting state support. Such state intervention is perhaps at its most serious when it takes the form of a denial of legal capacity – when the State refuses to recognise an individual as a holder of rights and an actor before the law (Mc Sherry 2012; Dhanda 2006-2007; Flynn & Arstein-Kerslake 2014). People with disabilities – especially those with cognitive disabilities, are among those at greatest risk of legal capacity denial (Flynn & Arstein-Kerslake 2014; European Agency for Fundamental Rights 2013).

People with disabilities and their representative organisations have long sought to challenge this discriminatory approach. In recent decades, they have challenged denials of legal capacity by seeking respect and recognition of their legal agency – on an equal basis with people without disabilities. This right was first explicitly recognised for people with disabilities in Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD). The scope and application of this right has been the subject of an emerging body of scholarship, and is also further discussed in previous articles within this volume. There is an emerging consensus on the need to remove discriminatory denials of legal capacity in light of Article 12, and calls for the

introduction of disability-neutral legislation (i.e. to replace discriminatory provisions such as the insanity defence and unfitness to plead) have also been made (Minkowitz 2014; Gooding & O'Mahony 2016).

In this article, we build on these approaches to argue for the abolition of disability-specific legal bases for state intervention in the private lives of adults. We also argue for the introduction of a narrower disability-neutral legislative framework for state intervention in the lives of all adults. In moving beyond the current discriminatory approaches, it is important to search for universal criteria for state intervention and describe how these might apply to all adults, rather than developing separate and more intrusive criteria for intervention which only apply to people with disabilities.

An important clarification which must be made at this point is that our approach seeks only to develop a theoretical framework for state intervention. We are aware that a potential criticism of our approach is that while the framework may appear neutral, like any legislative provision, it can be misapplied in practice, and this misapplication might lead to discriminatory outcomes for persons with disabilities. In order to guard against this outcome, we recommend that any implementation of the proposed theoretical framework must be subject to strict scrutiny to ensure that it does not discriminate in purpose or effect against persons with disabilities.

In this context, we define state 'intervention' as an intervention that is taken by the state or an agent of the state, which constitutes an interference with personal autonomy and may have the purpose or effect of denying the legal capacity of an individual. While the most obvious examples of state intervention occur through the criminal law, in this article we focus on civil law interventions, as these are the kinds

of interventions that people with disabilities most commonly experience in their private lives (Perlin 2013). We aim to ensure that in these instances, the state is still acting in accordance with Article 12 CRPD. In short, we do not believe that Article 12 disallows all state interventions which might result in denials of legal capacity. Rather, our view is that it requires that such state intervention be made on an equal basis for people with and without disabilities. In doing so, we want to push the boundaries of the existing law far beyond the current balance of autonomy and protection – to an approach which is much more respectful of the legal capacity of all adults – including people with disabilities. However, it is important to state that we believe our approach should result in less, rather than more, state intervention in the private lives of all adults. We also believe that our proposal should only be considered when the equal recognition of legal capacity required by Article 12 has been achieved. In other words, this proposal should not be taken out of context, or used by those who seek to retain elements of adult guardianship or substituted decision-making regimes in a post-CRPD world.

In this paper we will consider the issue of state intervention from two distinct perspectives. First, we will explore this issue from an equality and non-discrimination perspective. In so doing, we rely on Article 12 CRPD to provide a framework for recognising the discriminatory impact of existing legal capacity denials on adults with disabilities. Second, we will develop an alternative proposal for state intervention in the private lives of all adults, applicable to people with and without disabilities. In order to develop this proposal, we will draw some disability-neutral examples from current law that can support such a framework – such as domestic violence civil protection orders and public health powers.

Finally, we will suggest one possible definition of the point at which a power to intervene can be granted to state actors to protect an adult against a grave and imminent risk to life, health or safety. In so doing, we are conscious that this proposal is based on the political, social, cultural and legal contexts in which we, as authors, live – and we will not propose jurisdiction specific guidance in this article. However, we do draw on our knowledge of the legal systems in Ireland and the UK to provide illustrative examples of the current, problematic, state interventions in the private lives of adults with disabilities. We also acknowledge the serious damage which the state has historically inflicted on people with disabilities through its unwanted interventions,² and we seek to radically alter both the justification for state intervention and the nature and scope of these interventions.

We will provide some guidance on the nature and quality of the intervention permitted – and how the state can respond to emergency situations in a manner that continues to respect the individual’s legal agency. To support this argument, we will provide some illustrative examples of alternative state responses which should fully replace the use of force or coercion in these situations that can better respect the totality of an individual’s human rights.

In this article, we are particularly concerned about situations where a person is exploited or abused to the extent that they are afraid to seek outside support to leave a dangerous situation. We can and should work to create safe spaces where people can come to seek support, but these will never be truly accessible or open to people who

² For further reading on this point see for example, Minkowitz (2006-2007).

are isolated and segregated from society, or those in a state of domination as discussed in the previous article. We acknowledge that the state has historically not provided good support or effective responses in these situations. The most effective responses in our experience come from non-coercive methods developed by survivors and people with lived experience of exploitation, violence and abuse. We argue that these responses need to be scaled up with state support and should fully replace existing state interventions. However, we remain convinced that there will always be some scope for state intervention to respond to situations of suspected abuse and self harm using the civil law, albeit with a response that is radically different from the state interventions which currently occur.

State Intervention on an Equal Basis

Article 12 CRPD calls for equality before the law. This means that people with and without disabilities need to be equally recognised before the law and have their legal capacity respected on an equal basis (Committee on the Rights of Persons with Disabilities 2014, para. 12-15). State intervention may constitute an interference with the legal capacity of an individual in a number of different ways. For example, where a person runs into oncoming traffic in the presence of a police officer, the officer may rush to intercept the person and hold them back from the oncoming traffic. On one level, this could be viewed as an interference with the individual's legal agency as defined in the previous paper, as the individual is being prevented from carrying out an action which has legal consequences, which they may intend. However, intervention to protect the life of the person in such a situation, can, in our view, be permitted in a manner that respects international human rights obligations, and does

not violate the individual's right to legal capacity.³ The interventions required to proportionately respond to these dangers in a way that protects the totality of the individual's human rights will usually not amount to an interference in the exercise of the legal capacity. However, in some circumstances, the state intervention may amount to an interference with the right to legal capacity. In short, if a person is exercising legal agency according to the definition provided in the previous article (i.e. through an intended act or omission), (Arstein-Kerslake & Flynn 2017) and this exercise of legal agency places a person at risk of imminent and grave harm to their life, health or safety, we believe that a proportionate state response is required to protect the person's human rights.

Article 12 requires that state intervention, where it occurs, must be undertaken on an equal basis for people with and without disabilities – and that it cannot occur without first ensuring that persons with disabilities have equal recognition of their legal capacity and access to support, where desired, to exercise their legal capacity. The call for equality in Article 12 is not merely a call for formal equality. It is also a call for substantive equality. Formal equality before the law would only require that both people with disabilities and without disabilities have equal state interventions in their lives, regardless of the different circumstances in which individuals might find themselves. However, Article 2 of the CRPD requires freedom from discrimination in both purpose and effect (Committee on the Rights of Persons with Disabilities 2014). This means that the state cannot intervene on the basis of disability, as this would be a purposeful discrimination on the basis of disability. It also cannot create state

³ The authors wish to acknowledge the valuable insight of Tina Minkowitz who prompted us to more clearly define the situations where we believe state intervention is justified.

intervention that appears disability neutral, but only applies to people with disabilities. This would have the effect of discriminating on the basis of disability.

It should be noted that there are scholars who disagree with this interpretation of the CRPD and some have argued that an assessment of mental capacity can serve as the basis for state intervention and is not discriminatory on the basis of disability (Dawson and Szmukler 2006; Callaghan, Ryan and Kerridge 2013). However, the majority of the literature published since the entry into force of the CRPD supports the position that functional assessments of mental capacity discriminate (directly or indirectly) against persons with disabilities. This view is strongly held by those scholars who were most involved in the negotiations of the CRPD (Dhanda 2006-2007; Minkowitz 2006-2007), and is consistent with the interpretation of the CRPD by its treaty body, the UN Committee on the Rights of Persons with Disabilities.

Furthermore, Article 12(3) requires states to provide access to support for the exercise of legal capacity. This adds another element of substantive equality. It requires that states provide access to support for legal capacity instead of discriminatorily intervening in the lives of persons with disabilities. In almost all circumstances, the recognition of legal capacity and the provision of support to exercise it, will be sufficient to protect the totality of the individual's human rights. However, in some cases, the state may need powers to intervene in a person's life in order to offer her this non-coercive, human rights-compliant, form of support. Such intervention can be viewed as necessary in order to uphold the state's obligation to protect persons with disabilities from violence, exploitation and abuse, as outlined in Article 16 CRPD. We must ensure that the state's power to intervene in these situations is as narrow as

possible, and that it does not cause greater harm to the person by its intervention than would have resulted from a failure to intervene.

In seeking to develop a disability-neutral approach to state intervention that protects human rights, we are conscious of the experiences of other groups and a general scepticism of the benefits of state intervention. Much feminist literature has already described the dangers of state intervention that purports to ‘improve’ the lives of women, but in fact further entrenches patriarchal assumptions about women’s agency and decision-making. For example, Mills (1999) demonstrates how mandatory reporting of domestic violence, which was purportedly introduced to protect women’s rights, have actually resulted in the further marginalisation of many women and do not ‘promote the healing’ of survivors of domestic violence. She argues that state intervention is most effective when it is a ‘willing partnership’ between survivors and the state – not when coercive measures, designed to ‘protect’ women are imposed against their will (Mills 1999). We concur that the most human rights compliant state responses to people with disabilities will occur where the person is seeking state involvement and support, and we intend to demonstrate how survivor-centred approaches in a disability context can be supported and implemented by the state in our final section on non-coercive interventions, discussed below. We are only at the beginning of dismantling this disproportionate interference in the lives of people with disabilities – but we argue that all regimes of substituted decision-making must be dismantled, and all discriminatory denials of legal capacity abolished before any disability-neutral proposals for universally applicable, human rights compliant, state intervention can emerge.

Developing a Proposal for Permissible State Intervention for Everyone

Existing Interventions

There are various mechanisms for state intervention in the private lives of citizens. We recognise that many forms of state intervention are justified and form an important part of the role of the state. For example, it is arguably important for the state to have the power to remove children from the custody of parents in the interest of the child's welfare, health, or safety.⁴ Of course, it is essential to ensure that the state does not apply this power disproportionately to families of racial or indigenous minorities or other marginalised groups (Cunneen & Libesman 2000). Similarly, it is important for the state to have the power to intervene, with civil protection orders targeted at domestic violence, to remove a violent person from the family home if required to protect others living in the home. In this section, we will provide examples of state interventions that apply to the general population in order to highlight both those interventions which have the potential to provide Article 12 compliant protection for people with disabilities, and those interventions which are not compliant and constitute discrimination against people with disabilities.

There are some examples beyond disability, where individuals may be at risk of harm – even serious harm – but the state is willing to respect the individual as a decision-maker. This is generally the case with domestic violence. Courts can grant orders of restraint and other injunctions at the request of the individual at risk, but do not generally have the power to remove the individual at risk from the situation against her will or take another action that will deny her legal capacity or legal agency.⁵ In the context of human trafficking, there is evidence of a similar respect for the legal

⁴ See for example, Children Act 2001, Child Care Act 1991 (Ireland).

⁵ For a more in-depth discussion of the use of civil protection orders in domestic violence to respect women's legal agency see Hunter (2007) and Goldfarb (2007).

capacity of the individual. The Council of Europe Convention on Action against Trafficking in Human Beings specifically states that “each Party shall ensure that services are provided on a consensual and informed basis.”⁶

By contrast, problematic restrictions on legal capacity occur through the use of vulnerable adult protection orders, often explicitly targeted at older adults and people with disabilities whose behaviour is deemed to pose a risk to themselves or others (Dunn, Clare & Holland 2008). Protective orders can be used to remove vulnerable adults from their homes, for example, where the home is deemed by local authorities or social and health care professionals to be unfit for habitation. This may be due to hoarding (Thomas 1998), or neglect of personal hygiene, or other environmental concerns. Typically, these orders are designed to only be used on those who meet some criteria of ‘vulnerability’ (Williams 2002). This is often defined by disability or old age. Others who do not meet the criteria of disability or old age are permitted to go on living in environments which many might view as equally undesirable. These types of orders need to be critically examined to discover if they are discriminatory on the basis of disability. They should not allow for the intrusion into the life of a person with a disability to any greater extent than for a person without a disability, in order to be Article 12 compliant. However, the state’s legitimate impulse to protect its citizens may justify some power to intervene or respond in these situations. We will discuss below, in our proposal for non-discriminatory intervention, how the state could potentially act in such situations.

Facially-neutral state interventions for adults ‘at risk of harm’

⁶ Article 12(7), Council of Europe Convention on Action against Trafficking in Human Beings.

One example of an existing framework for state intervention in the lives of adults deemed to be at risk is the safeguarding provisions of the Care Act 2014 (England). Under this legislation, if a local authority has reasonable cause to suspect that an adult in its area (a) has needs for care and support, (b) is experiencing, or is at risk of, abuse or neglect, and (c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it; the local authority has a legal obligation to make enquiries to decide whether any action should be taken in the adult's case.⁷ The Act provides for assessments of need to be undertaken for adults in need of care and support, care plans to be developed for such adults, and places an obligation on local authorities to provide health and social care services to meet these needs for care and support (Schwehr, 2014).

Interestingly, this legislation also abolishes a previous provision in the National Assistance Act 1948 which gave local authorities the power to remove a person in need of care from their home.⁸ However, local authorities in England do retain powers to take action if they become aware that “any premises (a) are in such a filthy or unwholesome condition as to be prejudicial to health, or (b) are verminous.”⁹ Such actions include issuing a notice to the owner or occupier of the premises to take steps to remedy the condition of the premises and, in the event of failure to comply with such a notice, the local authority is empowered to take its own steps to rectify the condition of the premises and recover any expenses for such action from the person.¹⁰ These provisions cover all kinds of premises, including private homes, and are accompanied by powers of entry for local authority officials to carry out the actions

⁷ Care Act 2014 (England), s42.

⁸ Care Act 2014 (England), s46.

⁹ Public Health Act 1961 (England and Wales), s36.

¹⁰ Public Health Act 1936 (England and Wales), s83.

specified. Although this may not have been used to date to respond to adult safeguarding concerns, legislative powers of this nature, which are prima facie disability-neutral, can perhaps address some of the concerns about adults whose behaviour and living environment is creating a health risk to themselves and others. Such powers could accompany our specific proposal, discussed further below, for state intervention in the private lives of adults – as long as they are not disproportionately applied to persons with disabilities in such a manner as would constitute indirect discrimination.

However, it should be noted that while the provisions of the Care Act seem facially neutral, the eligibility regulations define ‘need’ for care and support in England as needs that ‘arise from or are related to a physical or mental impairment or illness’.¹¹ This approach stands in contrast to the recommendations of the Law Commission (2011), which sought to maintain disability-neutral eligibility criteria for adult social care, out of concern that those who would not identify as disabled would not then qualify for care services. In England, the notion of introducing formal safeguarding powers that would authorise powers of entry into the home of an adult thought to be at risk, was strongly resisted in public consultations on the Care Act (Department of Health 2013) and therefore no new powers to intervene were introduced. Ironically, however, while no new safeguarding powers were introduced in this Act, partly based on libertarian objections, the existing powers in the Mental Capacity Act would still permit the removal of an individual who lacks mental capacity from her home if such an action was deemed to be in her best interests.¹²

¹¹ Care and Support (Eligibility Criteria) Regulations 2014, s2.

¹² Mental Capacity Act 2005 (England and Wales), s3. An example of this use can be found in *Dorset County Council v EH* [2009] EWHC 784 (Fam).

From this brief overview of safeguarding powers in England, it seems that the attempt to use disability as the eligibility criteria for care and support services on the one hand, and mental capacity as the trigger for restrictive interventions in the name of adult safeguarding on the other, is creating serious problems in the enjoyment of fundamental rights for many adults with disabilities.¹³ Again, this approach suggests that disabled adults should expect to pay a high price for seeking the support to participate equally in society – that is, higher levels of intrusion and restrictive intervention in their lives. It entrenches prejudicial ideas about disability as arising from individual pathology rather than structural impediments, where vulnerability is conceived as inherent to the individual rather than arising from inadequate support, whether from state or from civil society.¹⁴ This approach further demonstrates that there is a perception that the only adults for whom restrictive state intervention is warranted in the name of safeguarding or protection are those with disabilities in need of care and support.

Legislative and Judicial Mechanisms for Safeguarding Adults ‘At Risk’

Adult protection or safeguarding powers can be created in legislation as described above, or can be developed by the courts through existing common law doctrine. While in our view, it is preferable to place some legislative boundaries around the exercise of judicial discretion to ensure that the rights, will and preferences of the

¹³ While the Care Act only places legislative duties to make enquiries about adults with disabilities perceived to be at risk of harm, it is arguable that there may be residual common law duties to make similar enquiries of other vulnerable adults. In *Re Z (Local Authority: Duty)* [2004] EWHC 2817 (Fam); [2005] 1 W.L.R. 959 the court set out this duty and noted that ‘In some context or other every human being is vulnerable’. An example of a non-disability related duty to protect from harm comes from *Commissioners of Police for the Metropolis v. Reeves (Joint Administratrix of the Estate of Martin Lynch, Deceased)* [1999] UKHL 35, where prisoners were identified as vulnerable and there was a duty to prevent prisoner suicide – notwithstanding that the prisoner had no “mental disturbance.”

¹⁴ With thanks to Piers Gooding for his feedback on this point from an earlier draft of this article.

person are respected,¹⁵ there is also a need to ensure sufficient flexibility so that the courts can provide a remedy in cases which would not fall within the scope of legislative safeguarding powers. There is an emerging trend in this field in the UK – where courts have relied on their ‘inherent jurisdiction’ to provide injunctive relief in cases involving so-called ‘vulnerable adults.’¹⁶

This approach is particularly interesting since it has been applied to adults who are deemed to have mental capacity – and indeed can be applied where the adult is simply seen as ‘vulnerable’ but does not have a label or diagnosis of disability. Thus, as an approach, it has the potential to be disability-neutral. However, in practice, from an analysis of the existing case law on inherent jurisdiction in England and Wales, it seems that the concept is disproportionately applied to adults with disabilities – and is often used to impose court orders on adults at risk of harm where the adult herself is not seeking this relief and may even object to the imposition of the order. Therefore, in seeking to explore whether the retention of a similar form of court discretion could accompany our proposal for legislative criteria to justify state interventions where adults are at imminent and grave risk of harm, we should consider the potential for such an approach to be applied in a truly disability-neutral manner.

The inherent jurisdiction to allow state intervention to protect vulnerable adults was invoked by Munby J in *Re SA*¹⁷ and by Singer J in *Re SK*¹⁸. In *Re SA*, Munby J

¹⁵ Article 12(4) CRPD.

¹⁶ This concept was first invoked in *Re G (an adult) (mental capacity: court’s jurisdiction)* [2004] EWHC 2222 (Fam). However, that case preceded the entry into force of the Mental Capacity Act 2005 (England and Wales). Therefore, subsequent cases have explored whether the inherent jurisdiction survived the passage of the Mental Capacity Act. In all the cases subsequently discussed in this section the courts have found that the inherent jurisdiction did survive the entry into force of the Mental Capacity Act.

¹⁷ *Re SA (vulnerable adult with capacity: marriage)* [2006] 1 FLR 867.

¹⁸ *Re SK (Proposed plaintiff) (an adult by way of her Litigation Friend)* [2005] 2 FLR 230.

justified the use of this jurisdiction by stating that ‘[a] vulnerable adult who does not suffer from any kind of mental incapacity may nonetheless be entitled to the protection of the inherent jurisdiction if he or she is, or is reasonably believed to be, incapacitated from making the relevant decision by reason of such things as constraint, coercion, undue influence or other vitiating factors.’¹⁹ Since persons without disabilities may be vulnerable, and may experience constraint, coercion, or undue influence which impact on their decision-making, this jurisdiction could in theory have a broad application. However, in practice, both cases concerned young women with disabilities from Pakistani and Bangladeshi Muslim communities respectively, who were perceived to be at risk of forced marriages.

In both cases, state intervention was authorised, in the case of SA to prevent her from being taken out of England without her consent to enter an arranged marriage, and in the case of SK, who had already left England for Bangladesh, an order preventing her from entering into marriage and prohibiting the use of threats, intimidation, harassment or violence was issued, with powers of arrest attached if the order was breached. However, if the purpose of the order issued by the court was to uphold the individual’s wishes (as for SA) or to discover the individual’s will and preferences (for SK), these orders would not constitute a form of state intervention that denies legal capacity – but rather a state response aimed at discovery of the person’s will and preferences – an approach which in our view, does not conflict with Article 12.

¹⁹ *Re SA (vulnerable adult with capacity: marriage)* [2006] 1 FLR 867 at para. 79.

The legitimacy of the inherent jurisdiction of the High Court was reinforced in a 2012 case, *DL v A Local Authority & Ors*.²⁰ This case was brought by a local authority which sought an injunction to prevent DL, a man in his 50s, from being aggressive, violent and abusive towards his elderly disabled parents, GRL and ML, with whom he lived. The order granted included a prohibition on DL preventing his parents from having contact with family or friends, seeking to coerce them to transfer ownership of the family home and move into a nursing home, interfering in the provision of care and support to his parents and behaving in a confrontational and aggressive manner towards care staff. At the time of the decision, both GRL and ML were deemed to have mental capacity to make decisions about whether their son should continue to live with them, but the local authority expressed concerns about DL's threatening and abusive behaviour and suggested that their ability to make decisions might be compromised by their son's actions.

However, in this case it is clear that the order against the son was not sought by the couple, and indeed it may not have accorded with their own wishes. In particular, the mother in this case had expressed a clear wish for the son to remain living at home – and the concerns about his behaviour arose from the local authority – not from the couple themselves. Therefore, if this order was sought without the couple's consent or in explicit contravention of their wishes, for a form of behaviour that would not amount to criminal activity, and in a situation where there was no imminent and grave risk to the couple's lives, health or safety, then this approach does not conform with our proposal, described further below, of the point at which state intervention in the private lives of adults is justified.

²⁰ [2012] EWCA Civ 253.

From this brief analysis, a number of tentative conclusions can be made about the effectiveness and legitimacy of existing state interventions in the private lives of adults. In terms of state interventions, these seem to work best and are less likely to disproportionately impact on marginalised communities when they are framed as situation specific interventions, imposed at the request of the affected party (e.g. domestic violence orders), rather than population specific interventions (e.g. protection orders for vulnerable adults) imposed at the request of law enforcement, local authorities or health and social care professionals. It also appears that state intervention can be most effective when it is flexible in nature – for example, in domestic violence protections where options are available that allow the parties to continue to live together as well as orders that require the perpetrator of violence to leave the family home. The use of state intervention also seems to work well when this is combined with other support – again, in the context of domestic violence, where orders are accompanied with offers of counselling, alternative housing, income support to achieve financial independence, etc. Finally, approaches which seek to penalise perpetrators of violence and abuse, rather than limiting the freedom of victims of such abuse, are needed.

Alternatives to Existing Approaches – Bach and Kerzner on ‘Serious Adverse Effects’

Since the entry into force of the CRPD, there is a growing awareness of the need to find disability-neutral approaches to state intervention in the private lives of adults. One of the best-known proposals to date to address this issue was developed by Bach and Kerzner in a paper for the Law Commission of Ontario in 2010, which proposed a

legislative definition of ‘serious adverse effects’ as a basis for state intervention in the lives of adults who use support in exercising their legal capacity. Bach and Kerzner (2010) draw on the existing legislation in Ontario – both in the Mental Health Act and adult guardianship law, to develop the following conceptualisation of where pre-emptive intervention can be justified to prevent adults from harm:

“A situation of serious adverse effects occurs when a person, as a result of his/her actions or those of others:

- a) Experiences loss of a significant part of a person’s property, or a person’s failure to provide necessities of life for himself or herself or for dependants; or
- b) Experiences serious illness or injury, *and* deprivation of liberty or personal security; or
- c) Has threatened or attempted or is threatening or attempting to cause physical and/or psychological harm to himself or herself; or
- d) Has behaved or is behaving violently towards another person or has caused or is causing another person to fear physical and/or psychological harm from him or her.” (Bach & Kerzner 2010, p.133)

In the statutory framework for state and provincial legislation on legal capacity in Canada subsequently developed by Bach in his role as Executive Vice-President of the Canadian Association for Community Living, an adult is deemed to be in need of state intervention where he or she 1) is in a situation of ‘serious adverse effects;’ and (2) is unable to act legally independently in the circumstances. Adults will be considered to be able to act legally independently within this framework if they have

the mental capacity to understand the nature and consequences of their actions. Under this framework, the proposed action which should be taken where a relevant Adult Protection Authority is notified that an individual is in a situation of serious adverse effects, or is 'at substantial risk' of being in such a situation would be to conduct an investigation, and the possible interventions permitted would be to provide the person with the option of entering into a formal support arrangement to exercise legal capacity, to revoke or restrict an existing support arrangement (where a supporter has placed an adult in a situation of serious adverse effects) or to 'facilitate whatever processes are provided for under this Act to ensure that the least intrusive and most autonomy enhancing arrangement is put into place.' (Canadian Association for Community Living 2012, p.39)

While the possible interventions described in the CACL framework seem relatively benign, the circumstances which trigger state intervention, as they are drawn from existing statutory frameworks, represent a very broad justification for intervention and in our view do not adequately balance the individual's dignity of risk with the legitimate state impulse to protect its citizens from exploitation and abuse. In particular, where the person is experiencing serious adverse effects by virtue of the actions of others, it seems overly interventionist that this should justify an intrusion on the privacy or freedom of an individual who may have already been exploited or abused – where a more appropriate response would be for legal consequences to attach to the perpetrator of such abuse. Similarly, the risk of loss of property, while it might be significant, is in our view, not sufficiently dangerous to warrant pre-emptive action on the part of the state or others who might wish to intervene in an individual's private life. After all, many people make decisions to gamble their property, and

while these choices may seem unwise to others, in most jurisdictions there is generally no way to prevent an adult from doing so – unless he or she has a label of disability or can be deemed to lack the mental capacity necessary to make the relevant decision.²¹

Bach and Kerzner's formulation of serious adverse effects includes both harm to self and harm to others. Since the emergence of Mill's (1869) harm principle, the notion of state imposition of legal restrictions on individual liberty based on harm to others has remained a more acceptable basis for intervention than the risk of harm to self. However, the most appropriate means of intervention – whether injunctive or consequentialist, in civil or criminal law, is still open to debate. According to Bach and Kerzner's (2010) proposal, where an adult's actions result in, or are substantially likely to result in, financial harm to others or physical/psychological harm to others, this forms a basis for preemptive intervention. Alternative legal remedies are generally available in these circumstances in both criminal and civil law – but many of these remedies can only apply after the harm has already been caused; although some remedies, discussed above, such as the use of domestic violence civil protection orders, are also designed for use to prevent future harm.

Those in favour of state intervention in the lives of adults based on a risk of serious harm to self tend to argue that if the State does not intervene to prevent the harm from occurring, it will end up intervening after the harm has occurred when the situation is more complex and the harm is often impossible to reverse. This reflects a utilitarian

²¹ For example, in the Peruvian Civil Code, Article 584 provides for an adult to be declared a 'prodigal' which results in a limitation of legal capacity if he or she has a spouse or heirs and squanders assets exceeding their disposable portion. No diagnosis of disability is required for this limitation of legal capacity.

approach whereby the greater good achieved by the intervention justifies this kind of restriction on individual liberty (Raz 1999; Hart 2012). Where no action would be taken by the State to prevent harm from occurring, many argue that families are left to ‘pick up the pieces’ – to try to repay the debts the adult has incurred, or provide accommodation if the person has lost their home through gambling, etc. These examples demonstrate how difficult it can be to draw neat distinctions between harm to self and harm to others – since self harm often impacts on those close to a person – both emotionally and financially.²² The point at which self harm impacts on others to the extent that it would justify state intervention will always remain a controversial issue. Of course, in many jurisdictions, the state would also have an obligation to support those who do not have the financial means to support themselves – regardless of how these circumstances arose. Similarly, where an individual experiences physical or psychological harm – there is also often a state obligation to provide support – through health and social services, in order to address these harms.

Nevertheless, Bach and Kerzner’s proposal is valuable in that it attempts to delineate a legislative basis for state intervention in the private lives of adults. This can be contrasted with the relatively unfettered judicial discretion described above in the UK through the use of the ‘inherent jurisdiction’ to justify protective intervention in the private lives of so-called ‘vulnerable adults.’ (Dunn, Clare & Holland 2008) However, the Canadian proposal still relies on a conception of mental capacity or legal independence which creates barriers for people with disabilities, and those perceived to have decision-making deficits in particular, in exercising legal capacity and fending off state intrusion. Therefore, we consider a different approach to the

²² For a discussion of the feminist critique of the Harm Principle, see Dyzenhaus, (1992); Harcourt, (1999).

point at which state intervention is justified in the private lives of adults, in the following section.

Our Proposal for Human Rights Compliant Intervention: ‘Imminent and Grave Harm’

To provide context for our development of the criteria of ‘imminent and grave harm’ as a basis for state intervention, it is worth briefly exploring our previous work on this issue. In the context of support to exercise legal capacity, we have previously argued that supporters must respect will and preferences ‘unless to do so would constitute criminal or civil negligence’ (Flynn & Arstein-Kerslake 2014). Gooding and Flynn (2015) build upon this approach in the context of the abolition of discriminatory mental capacity assessments for involuntary mental health treatment, and suggest that intervention by third parties is permissible here where the individual is at risk of ‘imminent and grave risk of harm, and failure to intervene would constitute criminal or civil negligence.’ The purpose of this proposal was to attempt to place legislative boundaries on the common law doctrine of necessity and to suggest how negligence law could be reshaped to further restrict powers of intervention for third parties.

In developing this concept further in the present article – we suggest that for any state duty to intervene imposed by the law of negligence, or by any other form of state power, the only criterion that can be used is that of ‘risk of imminent and grave harm to life, health or safety.’ An in-depth consideration of the law of negligence and its potential application in a disability-neutral manner – including the obligations it

places on third parties who are not state actors to intervene in the private lives of others is beyond the scope of this article. We acknowledge that any determination of what constitutes ‘imminent and grave’ harm is inherently subjective and value-laden, but suggest that in making this evaluation, state actors should have regard to the principles of Article 12 and should consider seriously the obligation to respect the legal capacity of persons with disabilities on an equal basis with others.

At this point it is worth clarifying what we mean by the term ‘state actor.’ For the purpose of this article we use this term to mean an agent of the state acting with powers or protection from liability guaranteed by the state – including social services, law enforcement and public health professionals. In this article, we will focus on the powers which these state actors should be able to exercise, as distinct from the protection from liability which individuals – including friends and family members – might enjoy for intervening in similar circumstances, which we view as beyond the scope of this article, although certainly worthy of further discussion, within the parameters of the criminal law and the law of torts.

It is important to clarify that this basis for state intervention creates a power to intervene, but does not impose a duty or obligation to intervene in every situation where imminent and grave harm is present. In other words, the existence of ‘risk of imminent and grave harm to life, health or safety’ is a necessary, but not always sufficient, criterion which must form the basis for any state duty or obligation to intervene. The purpose of our proposal is to constrain existing state power, not to expand existing state power or create a higher obligation on state actors to intervene than already exists in the current law. Since our proposal is developed as a response to

what people with disabilities perceive as intrusions into their lives by the state – we are anxious not to create more opportunities for state intervention in the lives of people with disabilities. This proposal therefore is intended to fully replace existing discriminatory systems which permit intervention in the private lives of adults based on a label of disability or a perceived lack of mental capacity.

The kinds of actions that would therefore be permitted under our proposed criteria would likely include powers of entry into an individual's home where a risk of imminent and grave harm is identified. Similarly, where a state actor is present during the infliction of self harm – the power to intervene could permit her to physically remove a dangerous object from the individual at risk of harm, or to physically remove the person from immediate danger – for example, to hold back a person who is threatening to jump from the top floor of a building. However, in our view the use of forced medication or force feeding by a state actor of an adult at risk of grave and imminent harm, including a person experiencing a mental health crisis or anorexia, would not be justified in order to respond to the risk of harm.²³ We discuss our reasons for drawing this distinction in further detail below.

In determining what actions can be justified during a state intervention, we turn to the proportionality test commonly applied in determining the extent to which state interferences with human rights are permissible (McHarg 1999; Grimm 2007). While

²³ In this context, we use the term 'force feeding' and 'forced medication' to refer to the imposition of treatment over the express objections of the person or by the use of coercive power (including legal authority) to ensure that the person cannot refuse treatment. This definition applies whether these objections are made contemporaneously or in advance, verbally or in writing. As discussed below, in situations where the person's will and preferences are unclear or appear to be conflicting, we argue that Article 12 must be applied to resolve the conflict in a manner that recognises and respects the legal capacity of the individual. With thanks to Alex Ruck Keene for drawing our attention to the need for this clarification.

we acknowledge that any determination of what action is ‘proportionate’ is inherently subjective and value-laden, in the same way that ‘imminent and grave harm’ is subjective, we currently have no other basis for determining the justification of such actions. Typically, the proportionality test has two elements – first, it must be established that the state intervention is in pursuit of a legitimate aim, and once this is established, we must consider whether this type of intervention is a proportionate response to the legitimate aim pursued. The protection of adults from harm is almost universally recognised as a legitimate aim (unless one adopts the libertarian approach that the state should never intervene to protect adults from self harm, which we reject). Therefore, the key question in the situations which we envisage flowing from a state intervention in situations of imminent and grave harm to life, health or safety, will be whether the particular response is a proportionate one – and in making this determination, regard must be had to any more creative, non-coercive options available to the state which would have responded to the individual at risk of harm without overriding her legal capacity.

Our reasoning for finding that forced medication and force feeding would be a disproportionate response to the legitimate aim of protecting the individual from harm is based on the testimony of survivors who identify the trauma and violence that forced medication and force feeding has caused – and the emerging literature which disputes the effectiveness of forced psychiatric medication in particular as a response to individuals in distress (Spandler, Anderson & Sapey 2015). We acknowledge that this perspective is not universally shared, and that some users of mental health services and medical professionals support the imposition of forced psychiatric

treatment.²⁴ However, in this paper we choose to align our position with those survivors who identify forced treatment as a violation of human rights. We do so because this perspective is increasingly supported by a growing body of scientific evidence which disputes the ‘benefits’ of forced psychiatric interventions, and is supported by some emerging case law where judges have refused to allow forced medical interventions over a person’s objections, even where the individual is perceived to lack the necessary mental capacity to consent to or refuse medical treatment.²⁵

Similarly, where an individual has made a legally binding advance healthcare directive refusing extraordinary lifesaving measures if their health deteriorates to a certain level, while their life may ultimately be at imminent and grave risk, we do not think that overriding the individual’s advance healthcare directive is a proportionate response where the individual’s circumstances remain unchanged from the position set out in the advance directive.²⁶ This is because, as set out above, imminent and grave harm is a necessary but not always sufficient criteria to justify state intervention.

We distinguish our approach in these cases from others who support the same outcome based on the capacity/incapacity paradigm. Others might argue that we reject the decision of the person in this situation on the basis that the person who is refusing to eat, or refusing medication ‘lacks capacity’ at the moment of the decision, whereas

²⁴ For further reading on users of mental health services and medical professionals who support the imposition of forced psychiatric treatment see, Stone & Stromberg (1976); Owen *et al.* (2009).

²⁵ For an example of healthcare professionals disputing the therapeutic benefits of forced psychiatry, see, Breggin (1994). For an example of a judicial rejection of non-consensual surgery even where the patient ‘lacked mental capacity, see Jackson J’s decision in *Wye Valley NHS Trust v Mr B* [2015] EWCOP 60.

²⁶ A determination of whether the person’s circumstances match the situation set out in their advance directive is an inherently subjective one and can be subject to differing interpretations. For more discussion on this issue, see Sehgal *et al* (1992) and Brett (1991). With thanks to Piers Gooding for drawing our attention to the need for this caveat.

the author of the advance directive had the required mental capacity at the time the decision was made (Halpern & Szmukler 1997) We do not agree that mental capacity should be the trigger for respecting or refusing to respect an individual's exercise of legal agency. As outlined in the paper by Flynn and Brosnan (2017) in this issue, we argue that medical practitioners have an obligation to communicate with the person about their treatment options, must ensure that the person has access to support where desired to express their will and preferences concerning treatment, and then respect the person's decision (including decisions made with support), even where it includes a refusal, regardless of the individual's actual or perceived mental capacity.²⁷

Wherever a state actor uses the power to intervene the nature of the intervention should be underpinned by a respect for the totality of the individual's human rights. While we urge caution in the use of this power by state actors and have sought to provide a very narrow definition of when this power can be used, we do advocate that in determining whether or not the power should be exercised, state actors must consider what action can best respect the totality of the person's human rights, including respect for the person's legal agency, bodily integrity and privacy – as well as the right to be free from violence, exploitation and abuse.

By contrast, wherever a state actor becomes aware that an individual is in a coercive relationship, or 'state of domination' (Pettit 2012; Friedman 2008) as explored in the previous article in this volume (Arstein-Kerslake & Flynn 2017), this does not, in our

²⁷ We have deliberately not made any distinction in this special issue between forced psychiatric treatment and other forms of forced medical treatment. While we acknowledge that many may believe that non-consensual administration of certain medication (such as antibiotics) is benign, we argue that an individual's right to refuse medical treatment must extend to all forms of medical intervention, no matter how benign, and respect for these refusals must not require the individual to demonstrate a certain level of mental capacity.

view, create a power to intervene – but it does create an obligation on the state to offer support to that person and to ensure access to different forms of support are available to the person. For example, if a social worker becomes aware that a person is experiencing coercion from a family member or sexual partner – she should offer support that could help the person to leave the coercive relationship, or find ways to address the coercive behaviour.²⁸ Where the person is not willing to leave the relationship but wants the state to provide her with some form of legal protection within the family home, this should be an option that is available, for example, through domestic violence orders as discussed above. As with all forms of support, where the person refuses the offer of support, the state has no basis for imposing support on the individual against her will.

In conclusion, we want to emphasise that this approach is based specifically on the legal, political, social and cultural context within which we as authors are located. In order for this approach to be adapted and implemented in any particular jurisdiction, there should be a fuller consideration of the levels of state intervention in the private lives of adults which would be acceptable in that particular society. This should form the basis for determining what kinds of disability-neutral interventions are permitted in that context.

Alternative State Responses that Do Not Amount to Legal Capacity Denial

Since the entry into force of the CRPD, the literature on new approaches to support people with disabilities to exercise their legal capacity has been steadily growing. Many of these approaches long pre-date the CRPD, but have come to international

²⁸ For more on the need for the state to provide a ‘right of exit’ to people who wish to leave situations of oppression or domination, see Okin (2002); Reitman (2005); and Spinner-Halev (2001).

prominence more recently, as states, and policy-makers in particular, seek alternatives to the imposition of adult guardianship and other forms of substituted decision-making. In this section, we will explore three well-known practices – open dialogue, family group conferencing, and circles of support – which can be used as alternatives to ward off state intervention in the private lives of adults – particularly focusing on people with disabilities. It is important to acknowledge in this context that many of these practices were first developed beyond the specific context of disability, and have now been adapted to work well for people with disabilities.

One of the most powerful examples of alternatives to state intervention in the lives of adults at risk is the use of open dialogue in Finland as an alternative to forcibly medicating adults experiencing emotional distress or mental health crisis. The approach was first piloted in Western Lapland, and has now spread to other pilot projects in Lithuania, Estonia, Norway, Sweden and Ireland (Seikkula & Olson 2003). Proponents of this approach describe it as a language or communication-based approach to psychosis. Open dialogue requires the involvement of the person experiencing the psychosis and their friends or family members in a partnership approach – where none of the participants are seen as the cause of the psychosis but rather as competent partners in the recovery process (Gleeson *et al* 1999). The open dialogue process begins with an initial meeting at the family home within 24 hours of the first signs of mental health crisis – and brings together mental health professionals, the person experiencing distress, and important people in her life – including peers, family and friends. The meeting takes place in a physically open forum, with all participants sitting in a circle. Crucial to the process is the fact that all decisions about potential treatment options or methods for diffusing the crisis are made with everyone

present – and by consensus – so that no separate ‘professional’ or ‘staff’ meetings are held where the ‘real’ decisions are made.

Seikkula and Olsen (2003, 408) cite ‘tolerance of uncertainty’ as one of the keys to a successful open dialogue process – but emphasise that this can only work if the environment is perceived as a ‘safe’ one – where the views of all participants are heard and acknowledged. In their view, ‘immediate advice, rapid conclusions and traditional interventions, make it less likely that safety and trust will be established, or that a genuine solution to a psychotic crisis will occur.’ This practice has now been in operation for over 25 years, and there is significant evidence that its use has decreased emergency hospitalisations, forced medication and recurrence of mental health crises (Seikkula & Aaltonen 2001). In this context, the use of open dialogue can be viewed as a proportionate state response to individuals in emotional distress or mental health crisis – in situations where the individual’s life or health is at risk of imminent and grave harm.

A similar approach, also based on dialogue between an individual experiencing difficulties and a group of supporters is known as Family Group Conferencing. This is a method of conflict resolution which emerged from Maori practice in New Zealand and became formally recognised as a mechanism for child care and protection in the Children, Young Persons and their Families Act 1989. Love (2007, p.21) describes how the concept derives from the Maori practice of ‘whanau hui’, a gathering of an individual’s extended family, to consider issues and make decisions with the aim of rebuilding harmony within the community. The process involves a partnership between family, community leaders, and childcare professionals from state agencies,

based on honest and open communication, facilitated by a co-ordinator appointed by the state, which leads to joint decision-making.

This practice has also spread beyond the context of child welfare and family support into youth offending, domestic violence, evictions, and more recently, into mental health services. In the Netherlands, for example, a pilot project, known as Eindhoven model of Family Group Conferencing in mental health care has been developed in order to prevent forced treatment. Santegoeds, a mental health activist involved in developing the model, advocates the abolition of forced treatment and describes how the model could be better implemented if forced treatment was not an option (Santegoeds, 2013). In the Eindhoven model, mental health professionals can be invited into the conference to give information or propose possible solutions, but unlike in open dialogue, the professionals are not involved in the development of the plan of action. Rather, the individual and supporters (peers, friends and family) develop the solution, in a private discussion after professional input has been received. De Jong, Schout & Abma (2014) describe how this pilot programme has successfully prevented involuntary treatment even in quite complex cases where individuals have experienced serious mental health crises, along with homelessness, perceived anti-social behaviour and other concerns.

Both open dialogue and family group conferencing are based on an individual and her supporters coming together to discuss possible solutions to a key question, or to resolve a conflict or crisis. While these processes are often activated in response to a crisis, the point at which state intervention is often triggered in an individual's life, their use on an ongoing basis can also help to prevent such state intervention. A good

example of the use of these mechanisms on an ongoing basis is the use of ‘circles of support’ or ‘circle of friends’ – a practice which has been used as part of restorative justice initiatives to support ex-offenders to reintegrate into society (Cesaroni 2001) – and has also been used to support persons with disabilities to plan for their lives (Gold 1994). In the context of disability, these circles are not typically formed in response to a crisis, but often rather developed as part of the transition to adulthood, to plan how the person can live a good life in their community.

Circles of support were initially developed to foster friendship and connections between disabled people and their non-disabled peers (Uditsky 1993), and are made up of an intentional group of supporters, often invited by the individual’s immediate family, but extending beyond family members to include neighbours, peers and friends. Gold (1994) explores the operation of one particular circle, for a young woman with significant intellectual disability, Leslie, where some members were initially invited by Leslie’s mother, but all had independent friendships with Leslie prior to the formation of the circle, and Leslie’s immediate family members were not involved in the group. Gold describes how circles such as this one can be viewed as part of a ‘sociology of acceptance’ and also within feminist understandings of friendship and support. This practice therefore has significant potential, especially when used on an ongoing basis to avoid the need for state intervention in the private lives of adults in emergency situations.

Conclusion

The problems with existing adult protection, safeguarding, and substituted decision-making regimes that permit state intervention in the lives of adults can be summarised

as follows – they are either premised on disability, a perceived lack of mental capacity, or a conception of the individual’s ‘inherent’ vulnerability. Most interventions which can be authorised restrict the person who is either experiencing, or at risk of abuse or exploitation, rather than the perpetrator, and the grounds for intervention are often extremely broad. In this article, we have persisted in the search for more disability-neutral legislative criteria that can be used to address the reality that many adults, both with and without disabilities, find themselves in situations which present imminent and grave risks to their life, health or safety. We believe that the state should be able to intervene to offer support and protection in these circumstances – although not to override the person’s autonomy if the person refuses to accept help. There are already examples of non-invasive supports which have been found to be more effective at managing risk than interventions which restrict the individual’s liberty – such as those described in the previous section. This demonstrates that effective non-invasive alternatives exist to restrictions or deprivations of the individual’s legal capacity.

At most, then, the purpose of any authorised state intervention is merely to explore the individual’s circumstances, and to determine what can be offered by way of support, rather than imposing unwanted protection or restricting the individual’s liberty. This is still invasive – but it is significantly less intrusive than existing measures which operate to restrict or deny legal capacity – especially to persons with disabilities. It also fits well with the philosophy of Article 12 CRPD, which posits that supports to exercise legal capacity can only be offered to people with disabilities, never imposed against the person’s will (Committee on the Rights of Persons with Disabilities 2014). Finally, there is a need to codify the criteria for intervention in legislation in order to

constrain judicial discretion to authorise a broad range of interventions in the perception that these would be in the ‘best interests’ of vulnerable adults.

The innovation in this proposal, as compared with previous attempts – is to permit state intervention in the lives of all adults, on a narrow range of grounds, i.e. situations of grave and imminent harm to life, health or safety. This is in contrast with existing law and policy that defines a narrow group of adults (based on perceived vulnerability, mental capacity or disability) in whose lives the state can intervene on a broad range of grounds. In practice, however, we accept that neat conceptual distinctions between these categories may be difficult to draw. This proposal will only gain traction if we accept that preemptive state intervention in situations of grave harm to individuals is a desirable goal – and if we are prepared to accept such intervention in all of our lives as a logical consequence of the social safety net we expect states to provide.

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