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Authors	Murray, Claire
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UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

3. Why care about carers?

Claire Murray

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Introduction

Rights are increasingly important in health law, both from a theoretical and a practical perspective. Respecting the autonomy and dignity rights of individuals should ultimately lead to more positive outcomes for people who engage with the health services because recognising them as rights subjects requires that they are treated with respect and their voices are listened to. Many of the chapters in this book are concerned with rights: identifying areas where rights have not been respected; teasing out how rights could best be protected; considering how to balance competing rights. The understanding of rights we are most familiar with is based on a traditional liberal approach which is very individualistic (Rawls, 1999; 2005). It conceives of the rights-holder as an individual existing in isolation and fails to acknowledge the reality that individuals exist in contexts – they are situated within communities and in relationships with others. Very often those relationships are caring in nature. However, a rights-based framework grounded in traditional liberalism cannot accommodate a dependent rights-subject. The result is that the position of carers and those who depend on care are not adequately recognised or supported within the legal framework.

This chapter argues that we should care about carers, and this should be recognised in the law, because this more accurately reflects the reality of people's lives

and because carers and cared for persons have highlighted the practical difficulties that arise when the legal framework fails to acknowledge this reality. As Kittay has observed 'when care is not adequately supported, either the cost of care is borne by the caregiver alone or the charge fails to receive adequate care – or both suffer' (2001: 575). If we accept that we should care about carers then it is very important that we think about how we conceptualise the caring relationship. This is because how we think about the caring relationship will impact on what a reformed legal framework which recognises carers looks like and how it operates. As Nedelsky notes 'a relational self requires relational conceptions of values, which then require appropriate forms of law and rights built around those conceptions' (2011: 5). In considering a contextual approach to rights, which is what a recognition of carers requires, it is possible to consider the carer and the cared for person as one unit or it is possible to see them as two separate individuals who are interconnected through the relationship of care. Each of these approaches gives rise to very different outcomes for the people involved and both will be interrogated in this chapter.

This chapter first considers why we should care about carers and engages with different theoretical approaches to recognising the caring relationship and the implications of this for those involved in such relationships. In particular the chapter considers an approach grounded in the ethic of care and one based on relational autonomy. The chapter then moves on to examine an area of Irish health law where carers are clearly excluded from the legal framework – the mental health system. The mental health system is a useful case-study as it illustrates the complexities around this issue. Ultimately this chapter concludes that it is important to care about carers, but

doing so must be in a manner which continues to respect the distinct individual rights of each of the parties to the caring relationship.

The situated subject, relational autonomy and rights

There are theoretical, legal and practical reasons why it makes sense to acknowledge within the legal framework that individuals exist in relationships with others. Arguably the strongest reason to do this is because it is in fact the reality of the situation. Feminist theorists and others arguing from a critical perspective have repeatedly highlighted the shortcomings of the traditional liberal rights-based model which is developed around the fictional abstract individual (Gilligan, 1982; Minow, 1990; Mullally, 2006; Sandel, 1998). Engagement with a more nuanced theoretical foundation for the legal framework, based around a situated subject, allows for the development of laws which more accurately reflect the lived realities of those directly affected by them. This ensures that the laws are more likely to effectively meet the needs of those they are designed to protect. At present there is a strong sense among carers that the work that they do is not recognised or appreciated by the State, and this impacts on both carers and those cared for.

Traditional liberal rights discourse is developed around the construct of the abstract, rational, autonomous individual. This rights subject is devoid of characteristics and is not connected to others. The individualist model of law is underpinned by this conception of the subject of rights. Critiques of traditional liberal rights discourse highlight the fictional nature of this subject and instead urge us to look beyond this traditionally accepted rights subject and instead to look to the realities of peoples' lives

(Sandel, 1998: 179). The process of critically engaging with this liberal construction of the subject of rights has led to the development within feminist theories of the concept of the situated subject. This involves recognising that people exist within relationships: with family, with carers, and in communities. Feminist theorists believe that such a subject – clothed in characteristics and interconnected to others – provides a more realistic foundation on which to base a theory of morality.

Ethic of care

One theoretical framework which centres on interconnection is based on an 'ethic of care.' The meaning of 'ethic of care' is not fixed and unmoving but Herring sets out a number of principles which underpin this theoretical approach (Herring, 2013: 49-64). The first is that care is part of being human and as such it should be valued. The second is that emotions are ethically significant. Thirdly, people are relational and their interests are interconnected. Fourthly, responsibilities are important. Finally, an ethic of care requires a rejection of abstract moral rules. In discussing the concept of interconnection, Herring states that 'emphasising interdependence and mutuality means that the division between carer and cared for dissolves' (2013: 166). This suggests that within this understanding of the ethic of care it is appropriate to view those in a caring relationship as one unit. Herring refers to 'give and take' in the carer and cared for relationship and highlights the importance of seeing decisions in the context of the relationship between the two people. According to Herring, this will avoid carers being treated as 'objects to be manipulated as part of patient care' (2013: 167). In what he acknowledges to be a controversial claim, Herring goes on to state that 'even an

interference in the wishes of a person with capacity can be justified when the relational context is taken into account' (2013: 173).

This version of the situated subject, and this conception of the ethic of care, raises concerns that it defines an individual too much in relation to others and it is in fact paternalism operating under another name. The risk is that the particular needs and rights of the individual subject become engulfed within the needs of the group or community or become overshadowed by the needs of the other party to the relationship. By stating that the ultimate consideration is the relational self, without the backdrop of a rights framework, we lose a valuable means of supporting weaker groups in society. This has the potential to cause particular difficulties for individuals who already tend to be recognised in relation to another, such as women, children, and people with disabilities. Another group that could come within this category are carers as they too are very often defined in relation to the person they are caring for.

Situated subject/relational autonomy

There is therefore a need to balance an awareness of the situated subject with an acknowledgment of individual rights that inhere in *each* person. This is at the core of relational autonomy theory (McKenzie and Stoljar, 2000). The concept of relational autonomy is subject to varied definitions (McKenzie and Stoljar, 2000; Herring, 2009; Sclater et al, 2009). However it often draws on critical feminist theories and as Nedelsky notes 'one of the contributions of feminism to relational theory is that it is particularly unlikely to make the mistake of romanticising community or relationship' (2011: 32). For the purpose of this chapter what is significant is that theories of relational

autonomy emphasise the individual in context while also retaining the importance of autonomy. Nedelsky sees the aim of relational autonomy as 'transforming a traditionally individual conception of the self into a relational one without subsuming the individual into the collective' (2011: 13).

This insistence on retaining the distinct rights of the parties while acknowledging their interdependence is particularly important in areas where individual rights have so recently been recognised, for example for people with disabilities. The challenge then is to develop a legal framework which balances the rights and interests of the parties to a relationship and which supports those involved in the relationship to ensure that it is a positive and functioning relationship to the greatest extent possible.

The conception of autonomy within a relational approach is different to that set out in the traditional liberal understanding. According to Nedelsky, under a relational approach autonomy is not equated with independence but rather 'autonomy is made possible by constructive relationships' (2011: 118). Therefore it is through the existence of positive relationships and supports, including relationships of care, that individuals are in a position to exercise autonomy. As noted previously, relational autonomy is a useful approach as it does not assume that all relationships are beneficial and it does not seek to maintain them in all circumstances (Donnelly and Murray, 2013: 399). A functioning relational approach to law therefore should operate to balance the rights and needs of both parties and allow individuals to extricate themselves from bad relationships and enhance positive relationships which support the exercise of autonomy. An approach that views the parties to a relationship as one unit, as discussed above, would make this much more difficult. Failing to have any regard for the needs

and rights of either party to a relationship of care will not contribute to developing a constructive relationship between the parties involved. It does not permit the carer or the cared for person to flourish or to exercise his or her right to autonomy and both are essential to the development and maintenance of positive relationships. Kittay argues from a relational perspective that those who advocate on behalf of people with disabilities (she is primarily concerned with people with profound intellectual disabilities) must look beyond liberalism, while still respecting the core values of autonomy and liberty, to 'seek conditions that are just to the caregiver as well as conducive to good care and justice for the charge' (Kittay, 2001: 562).

Human rights context

Article 8 of the ECHR protects the right to private and family life. This has been recognised as giving rise to rights for carers on their own behalf in England and Wales in the case of *R (A and B, X and Y) v East Sussex County Council and the Disability Rights Commission* [2003] EWHC 167 (Admin) and by the European Court of Human Rights in *Dordevic v Croatia* [2012] ECHR 1640. One of the key concerns for carers is an absence of information (Wilson et al., 2014; CPsychI, 2013). As noted by the REFOCUS group, carers 'wish to support the patient and the clinician in the process of recovery and, in this context, the provision of appropriate and agreed information is crucial' (CPsychI, 2013: 8). Article 8 could possibly be used to ground a right to information for carers within the legal framework. Herring states that if a decision is being taken by or in relation to an individual that would seriously impact on the carer then the carer's Article 8 rights will also be engaged (2013: 166). However it is important to note that the privacy rights of individuals are very important and must be respected and taken

into consideration, they cannot be disregarded because the person is in a caring relationship. As Nedelsky states 'to insist on the centrality of relationships in human lives is not to deny the value of privacy or solitude' (2011: 33).

While the ECHR has been interpreted as recognising some rights for carers, the position in relation to carers is not quite as strong in the Convention on the Rights of Persons with Disabilities (CRPD). The family is mentioned in the CRPD in the Preamble which states that:

> the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.

The Preamble, however, does not contain binding obligations and the CRPD itself does not include any distinct and independent rights for family members or carers (Kayess and French, 2008: 25). In fact the CRPD elevates the rights of the individual with a disability above those of the family members. Kayess and French state that the CRPD challenges the accepted construction of people with disabilities as burdens on family members and of always being in a dependant role within the family (2008: 5). Within the rights-based framework of the CRPD, people with disabilities are cast in an instrumental rather than a passive role. While this can be welcomed as a move away from a more controlling or paternalistic approach to people with disabilities, it is argued that it does serve to further perpetuate the individualistic model of rights. Yes, it is important that people with disabilities are seen as having an independent, autonomous existence and are not *always* viewed in association with family members/carers.

However, the other extreme is also unsatisfactory, where people with disabilities are viewed out of context, without acknowledging the very important familial and caring relationships which do exist. This chapter is based on the understanding that the reality is that all human beings exist within relationships and require care at some point and failing to recognise that within the legal framework results in laws which are not fit for purpose because they do not reflect the lived reality of those affected by them (Fineman, 2008; 2012).

That said there are also provisions within the CRPD which could be said to support a contextual approach and greater recognition of carers. Article 19 requires States Parties to recognise the right of persons with disabilities to live independently and to be included in the community, and this includes access to in-home, residential and other community support services necessary to achieve this (Article 19(b)). Article 12 of the CRPD concerns legal capacity and recognises the importance of support and assistance to facilitate persons with disabilities to make and communicate decisions and in this respect adopts a relational understanding of autonomy. The CRPD also places an obligation on States Parties to provide support to families and carers so they can fulfil the necessary support role for persons with disabilities (Article 12).

Having set out the theoretical and human rights justifications for why we should care about carers and argued in favour of conceptualising the caring relationship from a relational autonomy perspective this chapter now turns to examine the current Irish provisions in relation to carers in the context of the mental health system.

The current position of carers in the mental health system in Ireland

Government policy and medical practice is beginning to acknowledge the importance of carers of those with mental illness in Ireland but the legislation, the Mental Health Act 2001 (MHA 2001), is completely silent on the issue. This gives rise to a situation where the key stakeholders are moving towards a more relational approach but the underlying legal framework cannot support this. There are historical reasons for this situation; until very recently the individual rights of mental health service users were not recognised and very significant powers were placed in the hands of others, including family members and carers. As a result the MHA 2001 adopted a strictly individualistic approach to rights. Mental health law and the mental health system in Ireland therefore provides a useful case-study for considering the question of recognising carers as it illustrates the difficulties that arise when the law does not engage with carers but it also stands as a warning about the risks associated with neglecting the individual rights of vulnerable people. This section of the chapter will outline Government policy in relation to carers and highlight the difficulties identified by carers who engage with the system before setting out the current legal position. This will demonstrate the dissonance between the law and the broader operation of the system.

Government policy on carers

The National Carers' Strategy – Recognised, Supported, Empowered was published in 2012 (DOHC). This developed from a commitment in the Programme for Government (2011) to support carers. The Strategy sets out a vision statement that 'carers will be recognised and respected as key care partners. They will be supported to maintain their

own health and well-being and to care with confidence' (2012: 2). While this is commendable, the strategy almost immediately goes on to note the difficult financial circumstances in which the recognition of carers is being introduced and the proposals to reform the health system in Ireland and therefore commits to '[a]ctions for the short to medium term, which can, to the greatest extent possible, be achieved on a cost neutral basis' (2012: 4). Nevertheless it is significant that Government policy explicitly recognises that caring about carers is important and that the strategy recognises the need to support carers to provide good care but also to ensure that they maintain their own health and do not become socially isolated (2012: 9).

While carers are not explicitly recognised in the MHA 2001, they do feature in the Government policy on mental health set out in the Vision for Change document (DOHC, 2006). Chapter 3 is entitled 'Partnership in care: Service users and carers' and it notes that 'there is a need to formally recognise and support through practical means the crucial role of family care in mental health service provision' (DOHC, 2006: 28). The Expert Group recommended the provision of practical supports to carers such as access to information and education, planned respite care and inclusion in the care planning process (with the agreement of the service user) (2006: 29). However delivering on these recommendations has proved almost impossible in circumstances where there is no statutory obligation to recognise the role and position of carers in supporting the provision of mental health services and where limited resources have seen an increasing move towards what Carney characterises as the 'hollowed-out State' (Carney, 2008: 102).

Concerns of carers

In spite of these policy commitments, carers of people with mental illness continue to face challenges when engaging with the law and the mental health system. The REFOCUS forum of the College of Psychiatrists of Ireland published a paper on the needs of carers in 2013. The forum consists of service users and carers and the paper identifies ten themes, some interlinking and overlapping, identified by carers and it is worth setting those out. The themes are: the need for explicit recognition of the crucial role of carers; the need to acknowledge the unique impact of mental health difficulties of a family member on carers; the need for provision of information, knowledge and prognoses to carers; the recognition of the possible enduring nature of mental health problems; the use/abuse of patient confidentiality to justify lack of communication; the importance of continuity of care; the issues of aftercare and follow-up; the role and importance of support groups and self-help organisations; the need for a formal, robust complaints mechanism and information in relation to same; formal and structured recognition of carers as important contributors in the training of psychiatrists (2013). Many of these themes are also identifiable in the Government policy and strategy documents discussed above. This illustrates the disconnect between the aspirations of the service providers and the experience of those engaging with the service. In the conclusion to this document the College of Psychiatrists state that:

> the perspective of carers needs to be incorporated, and structured in a formal manner, into the curricula of trainee psychiatrists and ongoing CPD programmes. It is only in this way that the perspective of carers will have a transformative and enduring impact on the provision of mental health services in the country (2013: 12).

This is significant as it is important to ensure that any recognition of carers within the mental health system is taken on board by those charged with delivering the service at the front line. Experience with the implementation of the MHA 2001 has illustrated that changing the law alone is insufficient to ensure a change in practice (Murray, 2013). However, this chapter argues that a change in policy and practice alone is also insufficient. The changes in policy and practice outlined here are welcome developments but there needs to be a formal recognition of carers in the legal framework as well as without this, the contribution of carers and their rights and interests will remain invisible within the normative framework. The consequence is that the individualistic model of rights will remain, with the result that the rights and interests of one party in the caring relationship will continue to be prioritised over the other. This is not a just outcome for the carer or the cared for person.

Mental health law

The MHA 2001 was heralded as a rights-based model of mental health law when introduced and, given that it incorporated automatic periodic review of detention (section 17 and section 18) and enshrined the principle that people admitted under the terms of the Act could consent to treatment (section 56) for the first time in Ireland, this claim had a certain legitimacy. However the interpretation of the MHA 2001 by the courts and those implementing the statutory provisions has resulted in a reduction in the effectiveness of the rights-based model (Murray, 2013; Whelan, Ch. 14). The exclusive focus on individual rights in the MHA 2001 was in part a response to the very central role accorded to family members in the preceding legislation, the Mental Treatment Act 1945 (the 1945 Act). Under the 1945 Act there were many instances of

family members committing people into institutional care with very little oversight and, in the absence of adequate (or any) review mechanisms people could spend a considerable period incarcerated in inappropriate conditions (Prior, 2012; Boland, 2001; Boland and Laing, 1999/2000; Barry, 2009). Given this historical background, it is perhaps unsurprising that the MHA 2001 provides a very minimal and peripheral role for relatives/carers. However the consequence is that carers are almost invisible within Irish mental health law.

To the extent that carers have a role within the framework of the MHA 2001, it is in relation to involuntary admission – relatives and spouses (who very often fulfil a caring role) are included in the list of people who can apply to a medical practitioner for a recommendation for involuntary admission. The MHA 2001 states that a person may be admitted to an 'approved centre' on the basis that he or she suffers from a 'mental disorder'. The application for admission may be made by a spouse or (same sex) civil partner; by a relative; by an authorised officer (generally, a social worker); a member of the Garda Síochána; and, finally, by any other person (which may include carers who are not related to the individual). As noted elsewhere a 'relative' is extremely broadly defined and there is no statutory hierarchy of relatives, with all having an equal right to apply for admission (Donnelly and Murray, 2013: 386). The reality in Ireland is that the majority of involuntary admissions are commenced by the spouse or relative of the person admitted. This can have a detrimental impact on the relationship between the family members involved. In many instances it would be more appropriate for such an application to be commenced by an independent outsider. Unfortunately, there are very few authorised officers in Ireland and so this alternative route to admission is very often not available.

Once the application for a recommendation has been made, the role of the relative/carer disappears. Family members have no legal entitlement either to apply for discharge of the patient or to be informed in respect of the decision to discharge or of the discharge itself. There is no statutory requirement that the relatives/carers be given information relating to the rights of the individual who is involuntarily admitted even where the person admitted lacks capacity. Section 4(2) of the MHA 2001 requires that patients should be provided with notification of proposed recommendations or treatment and that they must be entitled to make representations in relation to the proposals. However, where the person lacks capacity, there is no legislative requirement to notify family members or carers and they have no statutory entitlement to make representations on behalf of the patient. The proposed capacity legislation is likely to address this shortcoming as there will be an obligation on medical professionals treating an individual to engage with carers where the carer is fulfilling a role under the terms of the capacity legislation. However this will not apply to all people admitted under the terms of the MHA 2001.

Finally, in any discussion of the absence of carers within the MHA 2001 it is important to note that the current legislative framework locates very considerable power with the medical profession. The lack of a role for carers could therefore also be a consequence of a heavily medicalised model of care and treatment which does not allow for any perspectives other than those of the consultant psychiatrist.

Conclusion

This chapter argues that the current individualistic framework for rights in healthcare fails to reflect the reality that individuals exist in relationships with others and argues that what is required instead is a contextual approach to rights. It is for this reason that we should care about carers and this should be reflected in the legal framework – at present the law is out of line with Government policy on this issue. However, it is important to take time to consider how we conceptualise the caring relationship as this will shape how carers are recognised in law and this will have consequences for both carers and those cared for. The chapter rejects an approach based on the ethic of care which sees the parties to a caring relationship as one unit because of concerns that the individual becomes subsumed within the bigger unit. This is particularly damaging for those who have traditionally not been recognised as rights holders. Instead the chapter argues in favour of adopting a relational autonomy approach which recognises the individual in context while continuing to respect the individual autonomy rights of the parties involved. Such an approach would ensure that the rights and interests of both parties are taken into consideration and this would be more likely to give rise to positive relationships of care which allow both parties to flourish.

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