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## **A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales.**

**Key words:** *Advocacy; Care Act 2014; Dementia; Mental Capacity; Mental Health; Human Rights; Convention on the Rights of Persons with Disabilities.*

### **ABSTRACT:**

*In this article we review current advocacy services for people with dementia in England and Wales (provided respectively under, the Mental Capacity Act 2005, the Mental Health Act 1983/2007 and the Care Act 2014) through the lens of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). We examine what a human rights' approach to advocacy support would entail, and whether current frameworks in England and Wales are adequate for this approach and provide a sufficient safeguard. First, we consider how the human rights of persons with dementia have become increasingly important and the extent to which the CRPD provides an opportunity to bolster the safeguards and protection. Second, we discuss cause and case advocacy, and how these advocacy models could be shaped by the CRPD to promote the rights of persons with dementia at each stage of the disease. Third, we highlight current dilemmas and challenges in the provision of advocacy support in England and Wales by focusing on case law, commissioning of services and current practice. In particular, we analyse how the different legislative schemes have given rise to some confusion about the various advocacy provisions, as well as potential for overlap and discrepancies between different regimes. We also highlight the need for further research to address important gaps in knowledge, including the scale of need, patterns of referral and attitudes to advocacy services. The article concludes by highlighting how advocacy support could be recalibrated as a universal right to promote the aims and aspirations of the CRPD, and how education is needed to address the stigma of dementia and promote the benefits of advocacy in protecting the rights of those with dementia.*

## Introduction

In recent years there has been growing recognition that action is needed to support the human rights of people with dementia. The World Health Organisation's (WHO) First Ministerial Conference on Dementia in 2015 focused on the global problems posed by dementia and how countries might co-ordinate national responses. The conference saw international organisations representing both people with dementia and Alzheimer's Societies making strong representations for a human rights approach (Dementia Alliance International, 2016). The WHO (2015) call for action and global action plan (WHO, 2016), which was adopted in May 2017, have since highlighted the importance of human rights of those with dementia, with the most recent plan stating that countries should, "promote mechanisms to monitor the protection of the human rights, wishes and preferences of people with dementia and the implementation of relevant legislation, in line with the objectives of the UN Convention on the Rights with Persons with Disabilities and other international and regional human rights instruments" (WHO, 2016, para 20).

This article explores, through the lens of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), how the rights of people with dementia might be supported through professional case advocacy. Our article focuses on England and Wales as a case study in order to highlight the strengths and limitations of promoting the rights of people with dementia in this way. In order to contextualise our argument, we begin by exploring wider debates about the rights of people with disabilities. We concentrate here on concepts of positive and negative rights, before going on to examine some of the opportunities and challenges raised by the CRPD. As dementia is a degenerative disease, we identify how models of rights may need to be adapted according to how advanced dementia has become in an individual. Case advocacy is then presented as a means of protecting human rights under the CRPD. We begin our case study by providing a critical account of why advocacy services were seen as an effective way to promote the rights of people with dementia in England and Wales. We describe how this led to overlapping and conflicting legal duties under the Mental Capacity Act 2005 (MCA), the Mental Health Act 1983 as amended by the Mental Health Act 2007 (MHA) and the Care Act 2014 (CA). We then examine current dilemmas and challenges, focusing specifically on case law, commissioning and current

practice. We conclude by considering how the rights of people with dementia might be better protected under a human rights' focused system, identifying areas for future research and lessons for countries developing law and policy to protect the rights of those with dementia.

### **Rights, Disabilities and Dementia**

It has increasingly been accepted that the rights of persons with disabilities, especially those with mental disabilities have, for too long, been overlooked and neglected. The development of a specific international disability convention in December 2006, namely the United Nations CRPD, 'is considered to be the culmination of the human rights struggle of people with disabilities' (Jones, 2005: 185). The CRPD has been described as heralding a 'new era' for people with disabilities (Lawson, 2007) as, for the first time, it views persons with disabilities as subjects and equal rights holders, and conceptualises key rights for persons with disabilities as positive entitlements. Traditionally, human rights frameworks, for example the European Convention on Human Rights (ECHR), have enshrined civil and political rights, so-called negative rights, thereby protecting, for example, the right to be free from torture/inhuman treatment, not to be discriminated against or not to be unlawfully deprived of one's liberty (Bartlett, P., Lewis, O. and Thorold, O., 2007). These rights have secured some important protections for persons with disabilities and there is jurisprudence at the European Court of Human Rights relating to the protection of the rights of persons with mental disabilities. Notably, the ECHR has provided procedural safeguards against arbitrary detention and minimum conditions of compulsory detention (see for example cases such as *X v UK* (1981); *Winterwerp v The Netherlands* (1979); *MS v UK* (2012)). Whilst there is no doubt that the European Court has made considerable progress in that regard, as some commentators have argued, there is still potential for 'a good deal more' (Bartlett et al, 2007; 17). In many respects, the ECHR and some other international treaty rights are limited, as they do not make specific reference to people with disabilities, nor do they always guarantee socio-economic entitlements and protection. The CRPD seeks to remedy this deficit, by giving people with disabilities positive rights and entitlements, including, for example, positive rights to housing, education and health. Indeed, Bartlett (2012) has recognised that the CRPD has 'the potential, if effectively implemented, to transform the lives of persons with disabilities' (2012, p. 753)

So how could the CRPD transform the lives of persons with dementia? The treaty does not define disability, but includes an expansive reference in Article 1 to ‘long term physical, mental, intellectual or sensory impairments’. This definition would undoubtedly include persons with dementia, as it has been described as ‘a major cause of disability and dependency influenced by symptoms, environments, discrimination and inequality’ (Batsch, N, Mittler, P and Kingston, D., 2017). For people with dementia, the CRPD brings with it the promise of ‘full and equal enjoyment of all human rights’, particularly in terms of ensuring access to health and community support and care, the nature of which varies depending on the stage of the disease and the severity of the symptoms. Foremost, the CRPD recognises that people with mental disabilities, including those with dementia, must be actively involved in decision-making in terms of the design and delivery of service provision and support (Article 4(3)); have a right to health without discrimination (Article 23), as well as a right to supported decision-making in order to exercise their legal capacity (Article 12(3)). Moreover, Articles 16 and 19 promote independent living and access to support services for habilitation and rehabilitation e.g. speech therapy; occupational health, physiotherapy; psychotherapy; specialist nursing and social work support. These articles suggest that advocacy support for persons with dementia should be designed to enable them to exercise choice and control over the range of appropriate support services to which they have access and maximise their ability to choose where and with whom they live. We address these issues in depth in the following section.

### **The aims and scope of advocacy services**

Advocacy refers to speaking on behalf of oneself or others. It involves making an argument in order to achieve a change in the circumstances of an individual or group. A review of the literature reveals a range of models, with sometimes overlapping or conflicting aims. In the following section we briefly review these definitions and identify how case advocacy might be used to support individual rights.

‘Advocacy’ is commonly used to describe the process by which one or a number of people seek justice or social change in relation to a specific issue. This type of advocacy can usefully be referred to as ‘cause advocacy’ (Rees, 1991), in which disempowered groups unite around a common cause to effect social change. This approach is often associated with activism.

Dementia advocacy of this kind is an emergent phenomenon, with organisations being formed at local, national and international levels with the purpose of lobbying for a human rights approach and holding governments accountable (Dementia Action Alliance, 2016). Drawing from the disability movement, these groups have used the demand, 'nothing about us, without us' to advocate for the voices of people with dementia to become central to policy making, service delivery and research (Shakespeare et al, 2017). This approach is very much aligned with that taken by Disabled People's Organisations and non-governmental actors to their involvement in the drafting of the CRPD (Sabatello & Schulze, 2014)

Our concern within this article is to focus on 'case advocacy' (Rees, 1991) where the focus is on an individual in line with the principles of the CRPD, although it is important to note that this may lead onto 'cause advocacy'. A number of types of case advocacy exist. Broadly speaking, the individual in question is either encouraged to speak for themselves (as is the case with self-advocacy) or is represented by a third party (Newbigging et al, 2015a). Where an individual is represented, the purpose is for the representative (an advocate) to make the views and wishes of that individual known. Individuals may be concerned with managing their own affairs or may wish to address social issues. Where this occurs an overlap between case advocacy and cause advocacy may take place, with case advocates enabling those with dementia to effect social change.

Supporters of case advocacy have argued that the aim is to persuade decision-makers to act on the views of the person being represented (Gostin, 1984; Wolfensberger, 1977). This aim might be achieved through highlighting the person's legal rights or through making complaints on their behalf. In this sense advocacy is not value neutral and involves acting on behalf of an individual. For this reason, it has been argued that advocates should be independent of the organisation they are making representations to. Advocacy may be provided by peers (such as one person with dementia supporting another) or by professionals. Whilst peer advocacy has been favoured by some activist groups, professional advocacy has become increasingly prominent since the 1970s, initially being developed in the United States, Austria and the Netherlands (Morgan, 2017).

Case advocacy provides a means through which governments can formally promote the 'rights, will and preferences' of people with dementia in accordance with Article 12 of the CRPD. As dementia is a progressive disease, which impacts decision-making ability, there is unquestionably a requirement for models of advocacy support to adapt over time to accommodate changes in need, in line with the person-centred ethos of the CRPD. In essence, this requires a responsive, focused and flexible approach to advocacy provision that places the person with dementia at its heart; and is regularly reviewed and modified to adjust to any deterioration in decision-making ability and /or changes in the level of support required.

Persons with mild dementia may require only 'dementia enabling' and rehabilitative support, i.e. the ability to 'remain active citizens in their own communities' and access to the range of services and opportunities that are generally available within those communities (Batsch et al, 2017; p. 2-3). Article 12 (2 and 3) of the CRPD states that people with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life and that nation states should take appropriate action to support individuals in exercising it. These Articles have been widely interpreted as a call for countries to adopt processes which enable 'supported decision-making', through which individuals are provided with the assistance to make and communicate decisions about their own wishes. (Dawson, 2015; Gooding, 2013). As dementia progresses, more extensive and specialist support will become increasingly necessary. For those in the later and end stages of the disease, the goal should be to ensure that they retain as much control over their lives as possible (Batsch *et al*, 2017). Debate continues as to whether the CRPD also allows for 'substitute decision-making', through which decision-making powers are delegated to another party via legal mechanisms such as guardianship (Dawson, 2015; Martin et al, 2014). This debate has led to countries such as Australia and Canada entering reservations that Article 12 should be interpreted as allowing substitute decision-making under certain circumstances (Richardson, 2012) and academics in the UK have also queried whether the CRPD does in fact prohibit substituted decision-making (Martin et al, 2014). Whilst this debate is ongoing, advocacy might provide a means through which the gap between supported decision-making and substituted decision-making might be bridged.

As advocates have a role in both supporting and representing individuals, they may enable supported decision-making. However, advocates may also engage in substitute decision-making through providing an expert interpretation on what an individual's wishes would be. Here, advocates would play a role in facilitating the provision of care and treatment without discrimination, which respects individual autonomy and preferences, and promotes inherent dignity, in line with Article 1 of the CRPD. As advocates have the potential to engage in both processes, the relationship established with an individual in the early stages of a condition such as dementia may be used to inform substitute decision-making once the ability of that person declines. This approach would allow advocacy support to be carefully calibrated in order to ensure that the voice of the individual with dementia continues to be heard at all stages in the progress of the disease.

### **Precursors and drivers to the legislation**

In the following section we develop our case study of how case advocacy has emerged in England and Wales. Here we outline how advocacy services were developed under the New Labour (1997-2010) and the Conservative / Liberal-Democrat Coalition (2010-15) Governments. We focus specifically on the MCA 2005, the MHA 1983/2007 and the CA 2014, since each of these Acts, for the first time, outlined statutory duties to provide advocacy, previous policy (DH, 2001; 2007) having only offered very general guidance. We begin by focusing on the MCA 2005.

#### The Mental Capacity Act 2005

The MCA was introduced in order to consolidate existing law and policy. Parliament had worried for some time about the demands on services that an aging population would bring; specifically on issues relating to advanced refusals of treatment and on how treatment decisions should be managed for those lacking capacity (House of Lords, 2003). Furthermore, concerns regarding the protection of rights for both older adults and people with learning disabilities had been expressed (Law Commission, 1995).

The Joint Committee on the Mental Capacity Bill (House of Lords & House of Commons, 2003) reported that numerous stakeholders supported the use of advocacy for those with capacity problems. The Committee concluded that advocacy played a crucial role in helping people to make their views known, determining best interests and safeguarding them from abuse. However, they stopped short of claiming that advocacy should be a universal right, on the basis that a duty already existed under the Disabled Persons (Services, Consultation and Representation) Act 1986 requiring Local Authorities (an administration body of local government) to provide advocacy for disabled people, but had not been enacted due to cost implications. Drawing on evidence from the Association of Directors of Social Services and the Health Minister, who had raised concerns about cost, the Committee recommended that advocacy provision be targeted at those lacking mental capacity.

### The Mental Health Act 2007

The Mental Health Act 2007 came into force in November 2008 to amend the Mental Health Act 1983, following two failed attempts to introduce a new Mental Health Bill in 2002 and 2004. A central driver for the reform was a belief by the New Labour Government that mental health law should have a greater emphasis on risk prevention and should allow for compulsory treatment in the community (Wright, 2002). The Government faced opposition to its proposals from a broad range of stakeholder and mental health interest groups, who together formed The Mental Health Alliance. Key concerns about the Bills were that they focused too heavily on public safety, whilst neglecting patient rights (Laing, 2003) and did not offer sufficient safeguards for detained patients (Cairney, 2009).

Advocacy was initially proposed as a safeguard by the New Labour Government as part of its first Mental Health Bill (DH, 2002). Whilst the provision of advocacy was welcomed by those scrutinizing the Bill, concern was expressed that the legislation did not go far enough, with the proposed eligibility criteria being viewed as too narrow and the proposed funding insufficient (House of Lords and House of Commons, 2005; Mental Health Alliance, 2006). In parallel to this, concerns had also been raised that patients had not been sufficiently protected from sexual abuse by psychiatrists, with advocacy suggested as one way of

safeguarding vulnerable individuals. The resulting amendment Act established new statutory advocacy powers aimed at those detained under the MHA 1983/2007.

### The Care Act 2014

The impetus to reform adult social care law was predominantly due to the fragmented nature of existing legislation, which had evolved in a piecemeal way since the 1940s. Whilst the bedrock of adult care law remained the National Assistance Act 1948, numerous other Acts affecting adult social care had been passed in the intervening years, making legal duties difficult to define (Law Commission, 2001). The resulting CA 2014 represented an attempt by the Coalition Government to consolidate and update existing law, taking into account the impact of the Human Rights Act 1998.

Whilst advocacy had not been highlighted as a specific topic for consideration by the Law Commission's consultation, it was raised by a range of stakeholders in their responses. As a result, the Law Commission recommended that the right to advocacy under the Disabled Persons (Services Consultation and Representation) Act 1986 be retained within the CA 2014, with a power for the Secretary of State 'to modify it to bring it into line with modern understandings' (p. 187). The Coalition Government rejected this proposal (DH, 2012). However, members of the Joint Committee on the MCA and the House of Lords argued for its inclusion on the basis that whilst the Care Bill emphasised choice, some parties might need advocacy to exercise it (House of Lords, 2013). Although the Government then conceded that advocacy should be provided, it again argued for a limited service. It was proposed that advocacy should be made available to those who had, "substantial difficulty in understanding, retaining, using or weighing the necessary information", to enable their involvement, as well as those who had difficulty in communicating their wishes and feelings; (House of Lords, 2013) and to adults involved in safeguarding investigations. In these cases, Local Authorities were given a duty to provide a service where no appropriate person, such as a friend or family member, was available to represent the person. Whilst funding was provided by central Government, it was not ring-fenced.

### **Implementation of the legislation**

It can be seen from the accounts above that each statute has introduced an explicit form of advocacy with distinct duties and powers (outlined below). For a person with dementia, advocacy support could be required under each legislative scheme in a range of different contexts and settings, which may result in some duplication and/or overlap. This situation reflects that the CA 2014 is intended to apply to *all* individuals with a care or support need, whereas the other two Acts apply only to more defined populations. In the following sections we consider the implementation of the CA 2014, followed by the MCA 2005 and the MHA 1983/2007.

First, under the CA 2014, an advocate is intended to enable the views or wishes of the individual to be communicated and heard where s/he is having 'substantial difficulty' in understanding what services are being offered by Local Authorities and there is no appropriate person to support them. This right applies broadly to the provision of care in all settings, regardless of whether the person lives in the community or in a care home. A person with dementia whose care needs are being assessed / reviewed may well experience 'substantial difficulty' in making decisions, for example, because s/he has memory problems or difficulty in expressing his/ her views, wishes or feelings. In this situation, the person fulfilling the advocate role could be a relative or friend, or a professional advocate may be appointed.

Second, the MCA 2005 introduced Independent Mental Capacity Advocates (IMCA) as a legal safeguard to provide support for people who lack capacity to make some important decisions, including making decisions about where they live and about 'serious medical treatment' options (see The MCA 2005, Independent Mental Capacity Advocates (General) Regulations). The Act provides that an IMCA must be instructed for people in the following circumstances:

- The person is aged 16 or over;
- A decision needs to be made about either a long-term change in accommodation or serious medical treatment;
- The person lacks capacity to make that decision; and

- There is no one independent of services, such as a family member or friend, who is 'appropriate to consult'.

There are also defined circumstances (set out in s. 39A, C & D of the MCA 2005) when an IMCA must be appointed for a person because they have been made subject to the Deprivation of Liberty Safeguards (DoLS). These safeguards are often used for people with dementia housed in residential or nursing care or hospital. The DoLS ensure that those deprived of their liberty within care settings due to restrictions or restraints, and who lack capacity to consent to their care, have their detention reviewed by two independent assessors. A deprivation of liberty is seen to occur where an individual is under continuous supervision and control and is not free to leave (*P v Cheshire West and Cheshire Council & Anor* [2014] UKSC 19; *P and Q v Surrey County Council; sub nom RE MIG and MEG* [2011] EWCA Civ 190). The advocacy role held by the IMCA under DoLS is narrower than for CA 2014 advocacy, and the IMCA's functions are narrower too. However, a person with dementia may be subject to a DoLS, or lack capacity to make decisions about their treatment, particularly when their mental capacity fluctuates and/or is deteriorating. So, in addition to advocacy support under the CA 2014, s/he may also be eligible for IMCA support in these circumstances. The functions of the IMCA are set out in the regulations and they are mainly instructed to support and represent those who have no one else, such as a family member or friend, who is able to represent them.

Finally, there are provisions in the MHA 1983/2007 to provide mental health advocacy for people who are detained in hospital under the formal provisions of the legislation. Should a person with dementia be compulsorily detained under the MHA, subject to guardianship or on a community treatment order (CTO), s/he has a statutory right to an Independent Mental Health Advocate (IMHA). The IMHA's role is intended to help patients to understand their rights under the legislation and to make their views heard. The IMHA's role is restricted to providing support only for those who are formally detained for longer than 72 hours under certain sections of the MHA.

### **Current dilemmas and challenges**

Dementia advocacy services have been significantly shaped by the MCA 2005, the MHA 1983/2007 and the CA 2014. Notably, none of these Acts is intended to deal specifically with the care needs of people with dementia. As the law does not define how advocacy provision should apply to specific groups, it is left to courts, commissioners and providers of advocacy services to interpret how they should apply legal principles to meet the distinctive and individual needs of people with dementia. The shape of services is therefore likely to depend on how the courts interpret and enforce the statutes, the adequacy of funding and commissioning, as well as professional and lay understandings of these new advocacy rights. We will now deal with each of these points in turn.

### Case Law

Some of the cases relating to advocacy have involved the circumstances in which individuals can expect advocacy provision and the speed at which the service should be delivered; although there are only a small number of relevant cases and most are not dementia specific. Nonetheless, they do clarify issues that will be of concern to this group. People with dementia are likely to have a broad range of needs which should be assessed under the CA 2014 (section 9(1)). The case of *R (SG) v London Borough of Haringey* (2015) established that, where an individual has been assessed as having a statutory right to advocacy, this service must be provided from the outset. In this case, the judge rejected the Local Authority's claim that their assessment was valid on the grounds that the person being assessed was on the waiting list for an advocate (because demand outstripped supply) (at para. 56). Other cases have established what those detained under the DoLS can expect. For example, the court found that failures to appoint an Independent Mental Capacity Advocate (IMCA) where individuals were subject to a DoLS amounted to a breach of the person's right to liberty under Article 5 of the European Convention on Human Rights (*London Borough of Hillingdon v Neary & Anor* [2011] EWCOP 1377). The *AJ (Deprivation of Liberty Safeguards)* case ([2015] EWCOP) concerned a woman with vascular dementia placed in residential care. The judge found that the appointment of an IMCA did not absolve the Local Authority from taking action to make sure that an individual had not been detained unlawfully. These judgments show that the courts will pay close attention to whether statutory rights to advocacy have been met. The cases are also useful in clarifying what the court believes the value of advocacy to be. For

example, in *London Borough of Hillingdon v Neary* the judge referred to the IMCAs report as “an impressive document” that subjected previous best interests’ judgments to scrutiny for the first time (para 123).

Nevertheless, there are still a number of unanswered questions for those with dementia. A statutory right to advocacy under the CA 2014 and MCA 2005 is dependent on there being no appropriate family member or friend available to assist the person. But it remains unclear in what circumstances support from family and friends would be deemed ‘adequate’ or ‘available’. In cases where a person with dementia has been made subject to DoLS, it also remains unclear what the role of the advocate should be. Doubt remains as to whether they should seek to represent the person’s wishes and feelings, or should seek to arbitrate between a care home and local authority (Bartlett, 2014). In addition, there has been no legal determination of whether Local or Health Authorities are expected to provide specialist advocacy services for people with dementia in circumstances when a right to a service exists. The availability and shape of dementia advocacy consequently remains highly dependent on commissioning at a local level.

### Commissioning

As there is no statutory duty for commissioners to provide dementia-specific advocacy services, individuals with dementia will be affected by commissioning decisions at a local level. Government evaluations of IMCA and IMHA services have highlighted wide disparities geographically that cannot be explained by population differences alone, although exact figures are not provided (CQC, 2015; DH, 2014). Recent reviews have identified an increasing need by advocacy services to demonstrate cost-effectiveness and a downward trend in funding for advocacy (Advocacy Action Alliance, 2015; Macadam, et al., 2013). For example, a survey of advocacy providers in England found that in 17 out of 21 Local Authorities, spending on CA 2014 advocacy was less than 60% of the total recommended by the Local Government Association in the previous year (Advocacy Action Alliance, 2015). Qualitative research with agencies providing dementia has identified that they believe that austerity policies are limiting their ability to provide an effective service (Brown, Syanden, & Khilji, 2013). Providers felt that, in order to win service contracts, they had to reflect the priorities

of commissioners, who preferred short-term interventions. This situation was viewed as problematic because it left providers feeling unable to cater for the specific communication needs of those with dementia and their long-term changing needs.

Whilst a number of studies have investigated levels of funding and commissioning practices, other gaps in knowledge remain. Most notably, it remains unclear what the scale of need for dementia advocacy services are and where resources might most effectively be deployed. We might reasonably hypothesise that the need for dementia advocacy under the CA 2014 is likely to be substantially higher than under the MCA 2005 or the MHA 1983/2007. This hypothesis is based on the grounds that the CA 2014 applies to *all individuals* with a social care need, whilst those lacking mental capacity or detained in hospital are likely to be smaller populations. However, such assumptions remain untested and it is unclear to what degree commissioning patterns reflect actual level of need. Researchers therefore need to consider ways in which they can measure the relative level of needs of people with dementia, their changing needs, as well as monitoring levels of dementia advocacy commissioning more generally.

#### Referral patterns and attitudes to advocacy

The provision of advocacy services will be affected by levels of professional referral and by awareness and levels of knowledge about advocacy by professionals and the public. A community care survey from April to September 2015 found that just 2% of people assessed under the CA 2014 during that period were given access to an advocate (Samuel, 2016). The Government had estimated prior to the passing of the legislation that 7% would qualify (*ibid*). Quantitative research into access to advocacy for people with dementia remains limited however. An analysis of 249 advocacy referrals made from 231 clients, conducted when IMCA services were being piloted, found that people with dementia accounted for 33% of accepted referrals overall (Redley, et al., 2010). Within these statistics, the authors noted that those with dementia were highly represented (60%) in referrals for an advocate where a change of accommodation prior to discharge from hospital had been proposed. However, the percentage of people with dementia referred for other decisions was unreported.

Despite limited quantitative data, qualitative studies have reported a number of factors which may affect levels of referral. Interviews with professionals have highlighted a lack of awareness amongst some about advocacy rights and revealed that others are confused about the difference between different forms of statutory advocacy (Chatfield et al., 2017; Newbigging, Ridley, McKeown, Machin, & Poursanidou, 2015b). Where professionals are aware of advocacy services, their attitudes may still affect referral rates. Professional attitudes remain mixed with several studies highlighting enthusiasm for advocacy amongst some on the basis that referrals protect individual rights and autonomy (Chatfield, et al., 2017; McKeown et al., 2014; Newbigging, et al., 2015b; Redley, et al., 2010). However, other professionals have indicated a cautious approach towards advocates due to fears that they might instigate complaints against them (McKeown, et al., 2014) or because they believe that advocates lacked the necessary skills to represent the interests of some groups, such as people with high clinical needs (Redley, et al., 2010). Qualitative research with advocates echoes many of these issues, with advocates noting that professionals had varying levels of knowledge about their role, which might impact on referrals (Chatfield, et al., 2017; Newbigging, et al., 2015b). However, research has also indicated that advocates may struggle to define their role (Newbigging, et al., 2015b; Redley, et al., 2010). Tensions existed between advocates who were happy to adopt a decision-specific model in line with legal requirements and those adopting an issue-based approach. Resistance to a decision-specific model arose from a worry that this approach might lead advocates to neglect the wider needs of service users in line with person-centred approaches to practice. Research focusing on user views to statutory advocacy is limited. However, Newbigging et al's (2015b) research found that service users tended to value the process of advocacy (such as experiencing advocates as supportive or empowering) and tended not to focus on statutory outcomes (such as a reduction in detention time or an increase in legal knowledge).

Future research is therefore needed which focuses on patterns of referrals for people with dementia. In line with Redley's et al's (2010) study, this could map referrals against statutory criteria for referral to an IMCA, but should also focus more broadly on the criteria for referral under the MHA 1983/2007 and the CA 2014. Future research could also identify attitudes to statutory advocacy within the range of dementia settings, as current studies have focused on advocacy and IMCA/IMHA services exclusively within hospital settings. The voices of people

with dementia are also missing from current research and this is of concern in light of focus in the CRPD on patient-centred and participatory approaches. Previous research into advocacy with older people with mental health problems prior to the types of statutory advocacy outlined in this paper indicated that 94.2% of service users surveyed were unaware of advocacy services (Brown & Standen, 2011). Future research might usefully identify levels of awareness about services for those eligible as well as identifying the degree to which such services were experienced as useful or supportive. In addition, the perspectives of dementia carers are missing from research. Future studies might usefully chart their level of awareness of current provisions. They might also identify whether carers would value an expansion in provision under the CA 2014 and the MCA, to allow for statutory advocacy in cases where those with dementia have family or friends.

## **Conclusions**

The CRPD brings great potential to remove barriers and provide support to enable persons with dementia to live as independently as possible and be central in decision making about their lives. On the positive side, the CRPD has raised awareness and increased the visibility of persons with disabilities; it has given a stronger voice to persons with disabilities and affirmed the need for support that is tailored and adapted to meet the specific and changing needs of individuals. However, one of the biggest challenges is securing implementation of the CRPD on the ground, as it is not directly enforceable within a domestic context in the UK and, has only persuasive influence. Implementation on the ground in a national context is therefore often dependent on political will and the provision of adequate resources (in both human and physical terms) to ensure that socio-economic rights become a reality.

Case advocacy provides one mechanism through which national states might promote a human rights approach for persons with dementia. This article, whilst highlighting the potential of advocacy for people with dementia, has identified shortcomings with the current state of advocacy provision in England and Wales. In this jurisdiction, there are widespread concerns about the complexity of the different statutory provisions as well as the potential for overlap and duplication. This complexity and overlap has created misunderstanding and confusion for health and social care practitioners working with the legislation on a daily basis.

We have also identified some failings with the current level of service provision, which is hampered by poor awareness and problems with resourcing and commissioning. The issues highlighted in England and Wales indicate concerns, which need to be taken into account if a clear, consistent and well-resourced advocacy system is to be put in place.

First, a universal right to advocacy should be given to people with mental disabilities, including those with dementia, who are eligible to receive health or social care services. As we have highlighted in this article, a number of special interest groups have lobbied for a universal right to advocacy for those receiving health and social care services. Government action to delimit when people can receive advocacy under different statutes in England and Wales were primarily impeded by financial considerations. This has subsequently led to an emphasis on the role of family and friends in facilitating communication, with professional advocacy being used where family is unavailable, or where there are safeguarding concerns. Whilst family and friends may indeed be best placed to represent individuals in some cases, it must be acknowledged that relatives may lack necessary knowledge and skills to negotiate with professionals for care and treatment. For example, research by Emmet et al (2014) has shown that some families of dementia patients struggled to safeguard their relatives' interests, as envisaged by the MCA 2005. This situation was due to their deference as lay-people to professionals, hospital procedures and, in some cases, other stronger-willed relatives. In addition, there may be cases in which those with mild forms of dementia come into conflict with family members negotiating their care. In these cases, they may benefit from an advocate to speak on their behalf. Consequently, there is a need for processes through which individuals with dementia can self-refer to advocacy services or be referred by others, where they lack mental capacity.

Second, case advocacy services need to be well-resourced and decisions about advocacy funding need to be informed by rigorous scoping exercises. As we have identified, Local Authorities and Care Commissioning Groups in England and Wales have varied widely in the level of advocacy services they have commissioned. Furthermore, commissioning decisions are made challenging due to legal duties to provide specific forms of advocacy under the different Acts of Parliament. Qualitative research and consultations with advocacy providers have highlighted that advocacy providers feel overstretched, whilst also being of the opinion that appropriate referrals are not being made (Brown, Syanden & Khilji, 2013; Law

Commission, 2017). However, much of the evidence available is anecdotal. For dementia advocacy services to be effective, scoping reviews need to be conducted to establish need at local levels, as well as measure the level of service currently being provided. Furthermore, the views of people with dementia need to shape commissioning decisions, in line with Article 33 (3) of the CRPD, which states that, 'persons with disabilities and their representative organizations shall be involved and participate' in the monitoring of the CRPD. In addition, research should identify how commissioners interpret their responsibilities under each Act of Parliament and how they seek to balance commissioning accordingly.

Third, for advocacy to be effective, its aims and objectives need to be clear. Advocacy services should ensure that people with dementia are enabled to maintain as much control over their lives as is possible, whilst recognising that their needs may change over time. It should be acknowledged that many individuals with early stage dementia will be able to represent themselves. However, as dementia progresses, individuals are likely to need more support for making their wishes known. As we have noted, Article 12 (2 and 3) of the CRPD states that people with disabilities should enjoy legal capacity on an equal basis with others in all aspects of their lives. Whilst we acknowledge that debate remains as to whether the CRPD allows for substituted decision-making, we contend that case advocates should enable both supported and substitute decision making. This approach would allow for advocates to expand or contract their level of involvement, in line with the changing needs of the individual. However, it is our contention that statutes should clearly delineate in what circumstances advocates should be expected to engage in each process. As we have identified in this article, advocates are given powers to help individuals with mental capacity to make their views known under the CA 2014 and the MHA 1983/2007. They are also tasked with identifying what the wishes of those lacking mental capacity would have been under the MCA 2005 and the MHA 1983/2007. However, the point at which advocates should engage in each process is made difficult and confusing by overlapping duties within each statute. Whilst this overlap has been acknowledged in England and Wales, debate as to how it should be remedied remains unresolved (Law Commission, 2017). However, in cases where advocacy services are to be developed in countries as a human rights mechanism for the first time, attention should be paid to how the duties to enable both supported and substituted decision-making can be aligned.

Fourth, education needs to be provided in order to promote advocacy services. As we have highlighted, it is unclear from current research how far people with dementia or their carers are aware of advocacy services. Research in England and Wales has revealed that advocates, as well as health and social care professionals, were often uncertain about when advocacy might be appropriate (Newbigging et al, 2015b; Redley et al, 2010). It has been suggested that this lack of knowledge might be addressed through professional qualifications for advocates as well as through education campaigns by local and health authorities outlining the benefits of advocacy (House of Lords, 2014). Whilst professional frameworks and public education campaigns about the law may go some way to promoting the rights of people with dementia, these would only partially address issues around the level of referrals. This is because professionals remain ambivalent about the value of advocacy, either because they prioritise ‘clinical’ perspectives or because they worry about the impact of complaints by advocates about their practice (Redley et al, 2010; McKeown, et al, 2014). Education about advocacy therefore needs to have broader aims focused on promoting a rights-based model of disability, in line with the principles of the CRPD. In promoting such a model, case based advocacy organisations might usefully build alliances with ‘cause’ based advocacy organisations, who are concerned with promoting the autonomy of those with dementia. The aims of awareness raising and educational campaigns therefore should be to identify and challenge the stigma experienced by those with dementia at a societal level, as well as highlighting case advocacy as one means through which the rights of persons with dementia might be protected at an individual level.

## References

- Advocacy Action Alliance (2015). *Commissioning independent advocacy under the Care Act 2014. A monitoring project for the Advocacy Action Alliance (AAA)*. London: Mental Health Foundation.
- AJ v A Local Authority*. [2015] EWCOP 5
- Bartlett, P. (2012). The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law, *Modern Law Review*, 75(5), 752-778.

- Bartlett, P. (2014). Reforming the Deprivation of Liberty Safeguards (DOLS) – What is it exactly that we want? *European Journal of Current Legal Issues*, 20(3), Web JCLI.
- Bartlett, P., Lewis, O., & Thorold, O. (2007). *Mental Disability and the European Convention on Human Rights*. Leiden/Boston: Martinus Nijhoff Publishers.
- Batsch, N., Mittler, P and Kingston, D. (2017). Brief for Alzheimer’s Associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by people living with dementia. Iowa: Dementia Alliance International & Alzheimer’s Disease International
- Brown, G., & Standen, N. (2011). Exploring the advocacy needs of older people with mental health problems in the West Midlands. *Working with Older People*, 15(1), 13-18.
- Brown, G., Standen, N., & Khilji, K. (2013). Dementia advocacy in a time of austerity. *Working with older people*, 17(2), 58-64.
- Cairney, P. (2009). The 'British Policy Style' and Mental Health: Beyond the Headlines. *Journal of Social Policy*, 38, 671-688.
- Care Act 2014*. London: The Stationery Office.
- Care Quality Commission (2015). *Monitoring the Mental Health Act in 2015/16*. Newcastle upon Tyne: Care Quality Commission
- Chatfield, D. A., Lee, S., Cowley, J., Kitzinger, C., Kitzinger, J., & Menon, D. K. (2017). Is there a broader role for independent mental capacity advocates in critical care? An exploratory study. *Nursing in Critical Care, Early Access*, 1-6.
- Dawson, J. (2015). A realistic approach to assessing mental health laws' compliance with the UNCRPD. *International Journal of Law and Psychiatry*, 40, 70-79.
- Dementia Alliance International (2016). *The Human Rights of People with Dementia: From rhetoric to reality*. Iowa: Dementia Alliance International.
- Department of Health (1999). *The National Service Framework for Mental Health*. London: Department of Health.
- Department of Health (2001). *National Service Framework for Older People*. London: Department of Health.
- Department of Health (2005). *Independence, wellbeing and choice: Our vision for the future of social care for adults*. London.
- Department of Health (2006). *Our health, our care, our say: A new direction for community services*. London: Department of Health.

- Department of Health (2007). *Putting people first: A shared vision and commitment to the transformation of adult care*. London: Department of Health.
- Department of Health (2012). *Reforming the law for adult care and support. The Government's response to Law Commission report 326 on adult social care*. London: Department of Health.
- Department of Health (2014). *The Sixth Year of the Independent Mental Capacity Advocacy (IMCA) Service: 2012/2013*. London: Department of Health.
- Disabled Persons (Services, Consultation and Representation) Act 1986*. London: The Stationery Office.
- Draft Mental Health Bill 2002*. London: Department of Health.
- Emmett, C., Poole, M., Bond, J., & Hughes, J. C. (2014). A relative safeguard? The informal roles that families and carers play when patients with dementia are discharged from hospital into care in England and Wales. *International Journal of Law, Policy and the Family*, 28(3), 302-320.
- Gooding, P. (2013). Supported decision-making: a rights-based disability concept and its implications for mental health law. *Psychiatry, Psychology and Law*, 20(3), 431-451.
- Gostin, Larry (1984) 'Foreword', in Bob Sang and John O'Brien (Eds), *Advocacy. The UK and American Experiences*, pp. 5-7. London: King's Fund.
- House of Lords (2003). *Aspects of the Economics of an Ageing Population* London: The Stationery Office.
- House of Lords (2013). *Care Bill [HL]. 21 May 2013. Volume 745*. London: House of Lords.
- House of Lords. House of Commons. Joint Committee on the Draft Incapacity Bill (2003). *Draft Mental Incapacity Bill. Session 2002-03. Volume 1*. London: The Stationery Office.
- House of Lords, & House of Commons (2005). *Draft Mental Health Bill*. London: The Stationery Office.
- H M Government (2005). *The Kerr/Haslam Inquiry*. London: The Stationery Office.
- H M Government (2007). *Putting People First. A shared vision and commitment to the transformation of Adult Social Care*. London: Department of Health.
- H M Government (2009) *Valuing People Now: A new three-year strategy for people with learning disabilities*. London: Department of Health.

- Jones, M., (2005). Can international law improve mental health? Some thoughts on the proposed convention on the rights of people with disabilities, *International Journal of Law and Psychiatry*, 28, 183-205.
- Laing, J. (2003). Reforming Mental Health Law and the ECHR: Will the rights of mentally vulnerable adults be protected? *Journal of Social Welfare and Family Law*, 25(4), 325-340.
- Law Commission (1995). *Mental Incapacity*. London: HMSO Publications.
- Law Commission (2011). *Adult Social Care*. London: The Stationery Office.
- Law Commission (2017). *Mental Capacity and Deprivation of Liberty*. London: The Stationery Office.
- Lawson, A. (2007). The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn? *Syracuse Journal of International Law and Commerce*, 34, 563.
- London Borough of Hillingdon versus Neary* [2011] EWHC 1377
- Martin, W., Sabine, M, Jutten, T., Burch, M. (2014). *Achieving CRPD Compliance*. Essex: Essex University.
- Mental Capacity Act 2005*. London: The Stationery Office.
- Mental Health Act 1983*. London: The Stationery Office.
- Mental Health Act 2007*. London: The Stationery Office.
- Mental Health Alliance (2006). *Alliance response to the Government's announcement of plans to amend the 1983 Act* Retrieved 08.06.17., 2017, from <http://www.mentalhealthalliance.org.uk/pre2007/response.html>
- Macadam, A., Watts, R., & Grieg, R. (2013). *The Impact of Advocacy for People who Use Social Care Services*. London: NIHR School for Social Care Research.
- McKeown, M., Ridley, J., Newbigging, K., Machin, K., Poursanidou, K., & Cruse, K. (2014). Conflict of roles: A conflict of ideas? The unsettled relations between care team staff and independent mental health advocates. *International Journal of Mental Health Nursing*, (5), 398-408.
- Morgan, G. (2017). *Independent Advocacy and Spiritual Care*. London: Palgrave Macmillan.
- MS v UK* [2012] ECHR 804.

- Newbigging, K., Ridley, J., McKeown, M., Sadd, J., Machin, K., Cruse, K., De La Haye, S., Able, L. & Poursanidou, K. (2015a). *Independent Mental Health Advocacy-The Right to Be Heard: Context, Values and Good Practice*. London: Jessica Kingsley Publishers.
- Newbigging, K., Ridley, J., McKeown, M., Machin, K., & Poursanidou, K. (2015b). 'When you haven't got much of a voice': an evaluation of the quality of Independent Mental Health Advocate (IMHA) services in England. *Health & social care in the community*, 23(3), 313-324.
- P and Q v Surrey County Council; sub nom RE MIG and MEG* [2011] EWCA Civ 190
- P (by his litigation friend the Official Solicitor) v Cheshire West and Chester Council & Anor* [2014] UKSC 19 (19 March 2014)
- Redley, M., Clare, I. C. H., Luke, L., & Holland, A. J. (2010). Mental Capacity Act (England and Wales) 2005: The Emergent Independent Mental Capacity Advocate (IMCA) Service. *British Journal of Social Work*, 40(6), 1812-1828.
- Rees, S. (1991) *Achieving Power: Practice and Policy in Social Welfare*. Allen & Unwin, St Leonards, Australia.
- Richardson, G. (2012). Mental disabilities and the law: From substitute to supported decision-making?. *Current Legal Problems*, 65(1), 333-354.
- Sabatello, M., & Schulze, M. (2014). *Human Rights and Disability Advocacy*. Philadelphia: University of Pennsylvania Press.
- Samuel, M. (2016). One year on, what has the Care Act achieved? from *Community Care* <http://www.communitycare.co.uk/2016/04/01/one-year-care-act-achieved/>
- Shakespeare, T., Zeilig, H., & Mittler, P. (2017). Rights in mind: Thinking differently about dementia and disability. *Dementia*, Online First.
- R on Application of SG v London Borough of Haringey* [2015] EWHC 2579 (Admin).
- United Nations. (2006). *Convention on the Rights of Persons with Disabilities. Treaty Series*, 2515, 3.
- Winterwerp v The Netherlands* [1979] ECHR 4.
- World Health Organization (2015). *Governments commit to advancement in dementia research and care*. Online. Available at: <http://www.who.int/mediacentre/news/releases/2015/action-on-dementia/en/> . Accessed 26.11.17.
- World Health Organization (2016). *Draft global action plan on the public health response to dementia. Report by the Director-General*. Online. Available at

[http://apps.who.int/gb/ebwha/pdf\\_files/EB140/B140\\_28-en.pdf?ua=1](http://apps.who.int/gb/ebwha/pdf_files/EB140/B140_28-en.pdf?ua=1) . Accessed  
26.11.17.

Wright, K. (2002). *Reform of the Mental Health Act 1983: the draft Mental Health  
Bill. Research Paper 02/80*. London: House of Commons Library.

*X v UK* [1981] ECHR 6.