

Mental Capacity Act (England and Wales) 2005: The Emergent Independent Mental Capacity Advocate (IMCA) Service

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Abstract

The Mental Capacity Act (England and Wales) 2005 (MCA) introduced the Independent Mental Capacity Advocate (IMCA) service to ensure that the views of adults who lack capacity to make particular potentially life-changing health and social care decisions are represented to substitute decision-makers. This paper presents quantitative and qualitative data from an evaluation of the pilot IMCA service that preceded the introduction of this new, statutory, form of advocacy. Importantly, our findings suggest that in more than half of the decisions completed during the period of the evaluation (54 per cent of 109 completed cases), clients were able to provide some indication of their wishes, enabling them to participate directly in personal decisions that they were unable to make autonomously. We discuss the implications of our findings both for the development of statutory advocacy in England and Wales and for other models of substitute decision-making.

Keywords: Mental Capacity Act, advocacy, decision making, health, social care

Introduction

In many jurisdictions, there is a general presumption that adults have the ability or ‘capacity’ to make decisions about their health, welfare and finances and to accept responsibility for the consequences of those decisions. However, when, as the result of a mental disorder, a person

lacks the capacity to make one or more decisions autonomously, it may be necessary for someone else to make the decision on his or her behalf. In substitute decision-making, tensions may arise between respecting a person's autonomy and shielding him or her from the risk of hardship, neglect, exploitation or abuse (Dunn *et al.*, 2007).

Legal frameworks to resolve this tension have focused on the regulation of the person or persons empowered to make decisions on behalf of, and in the interests of, the individual lacking capacity. In most jurisdictions, these frameworks have been based on a model of guardianship as mandated by Article 5 of the UN Declaration on the Rights of Mentally Retarded Persons (United Nations, 1971). Examples can be found in the jurisdictions of Japan (Arai and Homma, 2005), Ontario, Canada (Doron, 2002), South Australia and Scotland, where guardianship is provided through the statutory framework of the 2000 Adults with Incapacity (Scotland) Act. The legislation in these jurisdictions focuses primarily on the attributes of the substitute decision makers (their age, relationship to the person on whose behalf they are making decisions and so on), and how they are appointed and regulated (the circumstances under which they can, or cannot, make substitute decisions). The processes through which a guardian should reach a substitute decision, however, are not identified. In other words, these legal frameworks emphasise the *who* and the *what* of substitute decision-making. In contrast, the 2005 Mental Capacity Act (England and Wales) (MCA) focuses on how substitute decisions are to be made.

Prior to the introduction of the MCA, the situation for making substitute decisions for adults in England and Wales who lacked capacity was 'one of incoherence, inconsistency and historical accident' (Law Commission, 1995, para. 245). Some statutory regulation was available, under the 1983 Mental Health Act, but its scope was limited to decisions about the assessment and treatment of people with a mental disorder, primarily in hospital, and the management of the property and affairs of men and women who lacked capacity to make financial decisions for themselves. All other substitute health and welfare decisions were authorised under the common law, provided they were deemed both to be 'necessary' and in the best interests of the person on whose behalf they were made. Over time, the concept of best interests was developed by the High Court (see Dunn *et al.*, 2007, for a detailed examination), but, as Jones (2008) points out, these judgements provided a response to individual problems rather than a coherent legal framework that would protect and empower men and women unable to make one or more decisions for themselves. In contrast, the MCA provides a unitary legal framework for the regulation of substitute decisions where persons are unable to make one or more decisions for themselves because of a temporary, permanent or fluctuating 'impairment of, or disturbance in the functioning of, the mind or brain' (section 2(1) of the MCA). Importantly, the MCA does not cover those decisions involving the compulsory assessment and treatment in hospital of people with

serious mental health problems to protect their health or safety or that of others. In England and Wales, substitute decisions of this type are covered by the 1983 Mental Health Act (amended 2007), and there is a clear, albeit controversial (Dawson and Szmukler, 2006), distinction between the two pieces of legislation.

Substitute decision-making under the MCA, with some very limited, strictly circumscribed, exceptions (such as those following the appointment of a Lasting Power of Attorney or a Deputy, or involving particular kinds of intervention), is carried out by the individual requiring the particular decision to be made. In contrast with the model of guardianship adopted in Japan and other jurisdictions, this approach means that a range of individuals, including health and social care practitioners and family carers, can assume the role of decision-maker. In carrying out this role, they must ensure that they act in the 'best interests' of the person who lacks capacity, following section 4 of the MCA and its accompanying Code of Practice (2005 Mental Capacity Act Code of Practice, 2007, hereafter, Code of Practice, para. 5.13), which sets out the process (in the form of a 'checklist') by which best interests should be determined. This process includes consideration of at least the following factors: postponing the decision, if possible, until the person regains capacity to make the decision for him or herself; promoting, as far as possible, the person's participation in the decision-making process; taking into account the person's past and present wishes, feelings, beliefs and values; taking into account the views of others caring for the person or interested in his or her welfare; and all other relevant circumstances.

It was acknowledged elsewhere during the passage through Parliament of what later became the Mental Capacity Act that merely specifying the process by which a substitute decision should be made was unlikely to provide adequate protection to those who lacked decision-making capacity (House of Lords/House of Commons, 2003, para. 97 ff.). Nevertheless, a guardianship model was rejected. Instead, independent advocacy was proposed to ensure that the process had been followed appropriately. While the government recognised that the services of an advocate were desirable in many different situations, making advocacy universally available was rejected on the grounds of cost and practicality. It was, however, accepted that it should be provided in two strictly defined and potentially life-changing situations: those in which an adult lacking decision-making capacity is faced with: (i) a non-urgent 'serious medical treatment' (SMT); or (ii) a long-term 'change in accommodation' (CoA) where no prior relevant legal arrangements (such as a Deputy or Lasting Power of Attorney) have been made, and where the person has no family or friends whom it is 'practical or appropriate' for the decision-maker to consult about the person's wishes beliefs and values. Under these specific circumstances, section 35 of the MCA stipulates that a person is entitled to an Independent Mental Capacity Advocate (IMCA),¹ and that the

responsibility for the appointment of an IMCA lies with the individual who requires the decision to be made.

The Code of Practice for the MCA (para. 10.43) defines ‘serious medical treatment’ (SMT) in terms of a set of conditions: where it is proposed to start a new treatment, to stop an existing treatment or to withhold a possible treatment, and the benefits and burdens to the patient are finely balanced; or the choice between treatments is finely balanced; or the consequences to the patient are likely to be serious. According to the same document (paras 10.52–10.53), a ‘change of accommodation’ (CoA) is defined as admission to hospital or a move between hospitals that is likely to last more than twenty-eight days, or admission to, or move between, care homes for a period likely to exceed eight weeks.

The task of the IMCA is not to make a decision on behalf of the person lacking capacity. Rather, working within a time frame of around eight hours, and with a statutory right of access to the ‘relevant’ parts of the health and social care records, the IMCA’s primary responsibility is to ensure that the substitute decision-maker gives due regard to the person’s wishes, beliefs and values, including any relevant wishes expressed prior to the decision (for further details, see Code of Practice, Ch. 10). In addition, the IMCA can request a second medical opinion, challenge a decision-maker and, ultimately, where there are serious or urgent concerns, seek permission to refer the decision to the Court of Protection (Code of Practice, para. 10.32 ff.).

In England, the MCA requires NHS bodies and/or local authorities to commission IMCA services, while in Wales, this responsibility lies with Local Health Boards. So far, all the IMCA services commissioned in England and Wales have used existing advocacy organisations to provide what is, in these two jurisdictions, the first statutory advocacy service. The introduction of locally commissioned, but nationally regulated, advocacy services marks a significant turning point in the brief history of advocacy. Ten years ago, advocacy was characterised as *ad hoc*, uncoordinated and unregulated (Atkinson, 1999)—an observation that, but for the introduction of IMCAs, remains a fairly accurate description of advocacy in the UK (Armstrong, 2002). The defining value of successful advocacy, that is, independence from the decision-maker (Gostin, 1981), is, however, recognised in both the naming and commissioning of the MCA’s statutory advocacy service. Advocacy was initially conceived as a means of amplifying the *voice* of service users who, confronted by the power of social services, were in danger of having their wishes and autonomy disregarded (Henderson and Pochin, 2001). More recently, however, advocates have been representing the interests of people who are unable to express their wishes because they are unable to communicate or lack decision-making capacity. For these men and women, the task of advocacy in situations in which a decision needs to be made is to identify the likely impact of different choices and then advocate for the one that will maintain

or improve the quality of the person's life (see [Asist Advocacy, 2007](#)). While the introduction of statutory IMCA services will undoubtedly bring greater uniformity to advocacy, it is nonetheless based upon established advocacy values and skills. The Department of Health anticipated that each year there would be some 16,000 decisions in which adults lacking decision-making capacity would be entitled to the services of an IMCA ([Department of Health, 2005](#)).

Drawing upon findings from the evaluation of the pilot IMCA services commissioned by the Department of Health, this paper discusses the future development of statutory advocacy in England and the protection of adults lacking capacity to make one or more decisions for themselves.

Method

Fifteen months prior to the introduction in April 2007 of the IMCA service, the Department of Health invited seven advocacy organisations to provide pilot IMCA services. These organisations, all operating in the third sector and all based in England, were chosen to represent the diversity of the advocacy sector. Described in detail on the Department of Health's website (www.dh.gov.uk), these organisations variously represented older people, men and women with learning disabilities, and individuals with mental health problems. While some of the organisations relied only on paid advocates, others used a mixture of paid and volunteer advocates. The benefit to the organisations of taking part was the advantage they might have when tendering to provide the statutory IMCA service. As well as initiating this pilot IMCA service, the Department of Health commissioned a team of researchers to evaluate it.

The aim of the evaluation was to ascertain whether an IMCA service could protect the interests of adults who lack capacity and are without family or friends, and are faced with a potentially life-changing decision. In addition, we sought to identify and understand any practical difficulties that IMCAs might face following the introduction of the statutory service. To achieve these aims, the evaluation team (the authors of this paper), working closely with each advocacy organisation, collected quantitative data describing the number and types of referrals to the pilot IMCA service, and qualitative interview data capturing key stakeholders' experiences and perceptions of IMCA casework.

Ethical approval

Ethical approval for the evaluation was granted by the NHS Cambridge Research Ethics Committee on the understanding that no attempt would

be made to interview men or women lacking the capacity to give or withhold consent to participate in the research.

Data collection methods

The quantitative data were collected by asking each participating advocacy organisation to complete a twenty-two-item checklist describing each individual referred for an IMCA ('clients', in Department of Health terminology) and associated casework. Items on the checklist included prospective clients' demographics (including the reason for their lack of capacity and their primary means of communication); the profession of the person making the referral and the type of decision; whether or not the prospective client was considered eligible for an IMCA; and the casework involved in supporting each client (the numbers of meetings with the client, the total number of hours spent on the case, time from referral to decision, and whether health or social care notes were accessed). The checklist also included items to ascertain the outcome of each client's case and specifically whether the IMCA had been able to obtain information about his or her wishes or values; whether a written report had been submitted; and whether the IMCA challenged the decision maker's best-interests decision. The items on the checklist were discussed and piloted with representatives from each of the seven organisations, and the persons responsible for its completion were given face-to-face guidance in its use. Many of the items on the checklist included the category 'other', allowing free text responses. The final version of the checklist was presented in the form of an MS Access database, to be completed monthly and returned electronically to the research team. In the case of one organisation that experienced persistent problems running the Access database, a paper version of the checklist was used. Once entered into a master database, the monthly data were summarised using descriptive statistics.

The qualitative data were gathered by a series of interviews with:

- (1) each manager of an IMCA provider organisation, on two occasions: just after the pilot service was set up and, again, shortly before the MCA came into force (fourteen interviews);
- (2) one IMCA caseworker from each advocacy provider organisation, again, just after the start of the pilot service and then shortly before the MCA came into force (fourteen interviews);
- (3) the person(s) in each advocacy provider organisation with responsibility for ensuring that local health and social care services were aware of the pilot IMCA service (eight interviews);
- (4) the decision-makers in health and social care who, having worked with an IMCA, made a substitute decision on behalf of an adult lacking decision-making capacity (sixteen interviews);

- (5) health care practitioners who had not worked with an IMCA but who had some knowledge of both the MCA and the impending statutory IMCA service (thirty-five interviews).

The interviews with the IMCA managers, IMCA caseworkers and the person responsible for promoting the IMCA service (in some cases, the IMCA manager or caseworker) were conducted face to face at the offices of the participating organisations, and lasted between sixty and ninety minutes. A semi-structured interview schedule was designed to elicit participants' views and experience of: the IMCA role; promoting the IMCA service in health and social care services; the complexities of IMCA casework; working with decision-makers; the difference between statutory and generic non-instructed advocacy; and the perceived effectiveness of a statutory advocate in supporting the best interests of adults lacking decision-making capacity. The interviews with the decision-makers in health and social care who had worked with an IMCA, and the interviews with the health care practitioners who had not worked with an IMCA, were mainly conducted over the telephone. Using a semi-structured interview schedule, these interviews lasted between ten and forty minutes and were designed to elicit participants' views about whether the involvement of a statutory advocate had provided, or might provide, additional support both to people lacking capacity and to professionals making substitute decisions.

All the interview data were recorded contemporaneously by hand, with key phrases or expressions preserved verbatim. The interviewer was encouraged to adopt a challenging stance to the participants in order to develop a lively discussion (Holstein and Gubrium, 1997). All the data were then examined for content (Cicourel, 1964) and emergent themes were identified and coded. The codes and the subsequent analysis were refined and validated through the researchers' participation network meetings attended by IMCA caseworkers and their managers. These monthly day-long meetings, hosted in London by the Department of Health, provided a confidential forum for two or more representatives from each organisation to discuss with the civil servants, and members of the research team, problems associated with raising awareness of the pilot IMCA services amongst practitioners in health and social care, different interpretations of the IMCA role as set out in the MCA, and complicated or 'tricky' IMCA casework.

Data analysis

The analysis of the interview data began with identifying key issues around IMCA practice (e.g. the assessment of a client's capacity and whether family members might be appropriate to consult) and how these were

described and characterised. These descriptions became the basis for hypothetical models of IMCA practice. The models were tested and refined in subsequent interviews and at the monthly network meetings, and then used to provide nodes for data coding.

Findings

Starting with quantitative findings describing IMCA referrals, the IMCAs' clients and IMCA casework, this section moves on to report findings from the semi-structured interviews. However, where it makes more sense to report quantitative and qualitative findings together, we have done so. No quotations from the interview data are presented, as our intention is to report only the successes and challenges of IMCA casework in general, not the subjective experiences of individual interviewees.

In total, 436 referrals were made to the pilot service, of which 249 referrals met all the criteria for eligibility. The main reason for rejecting the remaining 187 referrals was that the person referred was found to have family or friends who could be consulted, but in approximately one in ten (11 per cent) cases, the person was subsequently judged to have decision-making capacity. Table 1 summarises the number of referrals for each type of decision. We present data from the 249 accepted referrals, involving 231 clients, sixteen of whom were referred twice or more for different decisions or because their circumstances had changed.

Among the 231 clients, the two largest groups were men and women whose compromised capacity resulted from learning disabilities (40 per cent) or dementia (33 per cent). The remainder were a heterogeneous group comprising adults with acquired brain injury, mental health problems, or a combination of these and other conditions. Only 3 per cent were people whose capacity was compromised solely by a physical illness. Decision-makers in health care were more likely than those in social care to have carried out their own assessment of an adult's decision-making capacity. Where social care decision-makers sought advice from another practitioner, this was almost always a psychologist or psychiatrist.

Almost two-thirds (63 per cent) of the 231 clients had family or friends who could, in principle, have been consulted, but this step was judged by decision-makers not to be 'practical or appropriate' (Code of Practice,

Table 1. Number of eligible referrals for each type of decision

Decision		Number of referrals
Serious medical treatment		37 (15%)
Change of accommodation	Prior to discharge from hospital	98 (39%)
	Other change of accommodation	114 (46%)
Total		249 (100%)

para. 10.77). The main practical barriers were, in order of frequency, that family or friends had not been in contact for a long time (30 per cent), were mentally or physically too frail (16 per cent), lived far away or were simply reluctant to be involved (8 per cent for both). In order of frequency, family and friends were not considered appropriate because of 'conflicts of interest' where it was felt they stood to gain or lose some material benefit as a result of a particular outcome (17 per cent), suspicions that they had abused the person lacking capacity (11 per cent), disagreements among different family members (3 per cent) or disputes with the decision maker (3 per cent).

There were some age differences between the referrals for the different decisions: men and women referred for a CoA prior to discharge from hospital were significantly older than those referred for the two other decisions. Not surprisingly, then, the majority (60 per cent) of referrals for decisions of this kind related to people with a diagnosis of dementia. Most of the referrals for other types of CoA decision related to people in the eighty to eighty-nine or thirty to thirty-nine-year age range, with the older group comprising men and women with dementia, and the younger group, people with learning disabilities. Among the older group, two-thirds (67 per cent) were moving from one residential placement to another. In the younger age group, the most frequent CoA decision also related to a move to a different residential placement, typically prompted by the closure of a care home or a change in the person's needs. The majority (60 per cent) of referrals relating to SMT were people with a diagnosis of a learning disability. The treatments of the thirty-five (of thirty-seven) referrals about which we were able to collect information were distributed across a range of medical specialisms, including oncology, orthopaedics, cardiology and palliative care.

While three-quarters (74 per cent) of the 231 clients used English or another spoken language, almost one in five (17 per cent) used an alternative means of communication (sign language, pictures or non-standard vocalisations). Only 6 per cent were described as having no obvious means of expressing themselves to others. Importantly, it was reported by the IMCAs that more than half (54 per cent) of the 109 clients whose referrals were completed at the end of the evaluation were able to communicate some indication of their wishes that could be passed on to a decision-maker.

Dealing with referrals

Overall, IMCAs spent just over nine hours on each referral. The mean duration of involvement was sixty-eight days and this did not vary significantly according to the type of decision.

Discussions with IMCAs revealed considerable uncertainty around the ending of their involvement with clients, particularly in relation to change

of accommodation decisions. From different perspectives, a case might be considered to have ended when the client's needs and preferences had been identified and communicated to a decision-maker, when an appropriate care home had been identified, or when the person had moved into his or her new home. There was a consensus among the IMCAs that their involvement *should* end only when a decision had been made *and* implemented fully. The Code of Practice requires decision-makers to keep IMCAs informed of developments (para. 10.14), and to make available in a report the information and issues that they believed to be important in respect of a particular decision (para. 10.20). In fact, the IMCAs reported that they often felt 'out of the loop' and that it was rare for them to receive any response to, or even acknowledgement of, their written reports.

One hundred and nine of the 249 referrals were completed during the course of the evaluation. In only sixteen (15 per cent) of these did the IMCA challenge the decision that had been made. Ten of these challenges related to judgements of incapacity. The clients involved in three of the referrals were reassessed, and, in two cases, were subsequently found to be able to make the particular decision autonomously. A further six challenges, made through letters and telephone calls to the decision-maker or his/her manager, related to substitute decisions about CoAs (three prior to discharge from hospital; three relating to other changes). Three of these challenges received no response but in one case, in which the IMCA was able to discuss the matter with the decision-maker, the original decision was revised.

The IMCA role

Few practical difficulties, such as in interviewing clients privately or examining their records, were reported. Rather, what exercised IMCAs and their managers the most was 'the IMCA role'. In contrast with the most commonly used models of advocacy, which emphasise the importance of taking time to get to know a client prior to representing his or her wishes on a wide range of issues, IMCA advocacy is decision-specific and expected to require an average of only eight hours' work per client ([Department of Health, 2005](#)). Over the course of the pilot, there were changes in the views of both those IMCA advocates who were strongly committed to a person-centred approach and those IMCAs who were more comfortable with decision-specific advocacy. Ultimately, these opinions led to a consensus, expressed in the words of one advocate, that, at its best, the role of an 'IMCA is decision-led but client focused'. Decision-makers in both health and social care expressed positive views of involving advocates in substitute decisions about CoA. More specifically, the decision-makers in social care were impressed with the IMCAs' knowledge, feeling that they shared a common language. Furthermore, they were enthusiastic about advocacy,

viewing it as a means to enhance their understanding of a client's needs, as an aid to communication between members of multi-agency teams, and as a reminder of the centrality of the client's interests when making a substitute decision. The seven health care decision-makers who had worked with IMCAs in CoA decisions for in-patients expressed similar views. They, too, reported that they had been impressed with the service they had received, though some concern was expressed over the possibility that advocates had contributed to slight delays in the process of discharging a patient from hospital. Only two of the health care decision-makers had experience of working with an IMCA in a decision relating to a SMT decision. Both reported that their initial scepticism had been challenged by the experience and that statutory advocacy had made a useful contribution to the decision-making process.

Of those health care decision-makers who had not worked with an IMCA, the majority expressed reservations at the prospect of having to involve an advocate in decisions relating to a SMT. Four main concerns were expressed: first, doubts about the contribution that could be made by anyone without medical training; second, scepticism about the professional ability of advocates to represent clients' views; third, that advocacy was unnecessary, since, as health care practitioners, they themselves already acted in the best interests of their patients; and, finally, that a service available only within office hours was unhelpful. In striking contrast, the same respondents were enthusiastic about the involvement of an IMCA in CoA decisions arising in the context of patients being discharged from hospital. These decisions were not seen as entirely medical and, therefore, the involvement of an advocate, offering a lay person's perspective, was considered to be both appropriate and possibly of considerable value. It was anticipated that IMCAs might be able to resolve many of the difficulties currently facing hospital discharge services, particularly poor communication between health and social care teams, and delays and difficulties in securing funding for residential placements.

It was apparent, however, from our interviews with these health care decision-makers that many of them did not fully understand the MCA's decision-specific approach to capacity. Instead, capacity seemed to be viewed as a global construct, which could be judged on the basis of standardised measures of cognitive functioning (such as the Mini-Mental State Examination (Folstein *et al.*, 1975)), or described idiosyncratically using terms such as 'partial capacity'.

Discussion

The purpose of these findings from the pilot Independent Mental Capacity Advocate (IMCA) service was to inform the development of statutory advocacy, introduced in English legislation for the first time under the

2005 Mental Capacity Act. The aim of such advocacy is to represent to substitute decision-makers the views of adults ('clients') lacking suitable family or friends, who are unable to make a decision for themselves in relation to serious medical treatment or a change of accommodation because of a temporary, permanent or fluctuating 'impairment of, or disturbance in the functioning of, mind or brain' (section 2(1) of the MCA).

It should be borne in mind that the data presented here are derived from a pilot service, whose organisations were selected for the pilot in part because they were already judged able to deliver an IMCA service. Hence, the quantitative data may not be an accurate representation of the true proportions of IMCA cases with respect to decision types and the demographics of the client groups. In contrast, the managers and IMCA caseworkers interviewed for the qualitative data probably represent some of the most able advocates because the organisations from which they came had been selected by the Department of Health to take part in the pilot.

Our findings showed that, while the IMCA pilot service represented people with a broad range of conditions, the main clients were men and women with learning disabilities or dementia. Very encouragingly, for more than half the decisions completed during the evaluation, clients were able to indicate their views. This enabled IMCAs to support these men and women directly in participating in decisions made on their behalf. The important implication of this finding is that legal frameworks, such as those of Japan, Ontario, South Australia and Scotland, which are based on guardianship models and focus on the attributes, appointment and regulation of substitute decision-makers, rather than on the process by which such decisions are reached, may be insufficiently nuanced. By focusing on the protection of people who are judged to lack capacity, their potential contributions to personal decision-making are overlooked.

As the pilot IMCA service developed, the advocates gained greater understanding of, and confidence in, their role, conceptualising it as decision-specific but client-focused. Despite some struggles, they also seemed to be able to contain their involvement. At nine hours, the mean direct time spent on each referral was hardly higher than the average of eight hours recommended by the [Department of Health \(2005\)](#). Nevertheless, there was some evidence of difficulties. First, and rather worryingly, there was a mean delay of more than two months between the initial acceptance of a referral by an IMCA and the end of his or her involvement. While such long delays for SMT decisions seem surprising, they appeared to reflect the medical complexity of many of the decisions (e.g. where investigations were needed or liaison between different specialties was required). For CoA, however, the delays appeared instead to reflect the concerns of the IMCAs and, in particular, their sense of having a responsibility to support clients until the decision had been implemented fully. Such high levels of commitment to some clients may undermine IMCAs' ability to respond effectively to other clients. Anyway, this type of commitment

may not be feasible if the impact of expansions of the role of IMCAs (Statutory Instrument 2006/2883; Statutory Instrument 2007/852 (W.77)) outweighs the effects of the more circumscribed definition of not 'practical or appropriate' to consult that has now been introduced (see Code of Practice, 2007). As has been argued elsewhere (Redley *et al.*, 2006), it would be much easier for IMCA advocates to contain their involvement and adhere to their decision-specific remit if generic advocacy services, to which they could make referrals, were more widely available.

Second, while IMCAs reported no difficulties in gaining access to interview clients privately or examine their records, there were some problems around communication with decision-makers. Surprisingly, while advocates readily expressed concerns that clients' best interests were being defined by current practice and the options immediately available rather than by a proper consideration of the processes expected under the MCA, the number of formal challenges to decision-makers' judgements and substitute decisions was limited. Indeed, there were no challenges at all to SMT decisions. Both IMCAs and their managers suggested that, at least in the early stages of the pilot services, they experienced considerable tension between their responsibility to clients and the need to develop and maintain constructive relationships with decision-makers. This tension may have been exacerbated by the IMCAs' perception that they were frequently marginalised. Unless good communication, both orally and in writing, is established, it is impossible for them to ensure that best interests procedures (Code of Practice, Ch. 5) are followed.

The evaluation highlighted important differences between the various decisions. Regardless of whether or not they had experience of working with one or more IMCAs, health and social care decision-makers were generally very supportive of the need for, and potential benefits of, the involvement of advocates in CoA decisions. Indeed, among potential health care decision-makers, there was a high level of enthusiasm. However, this seemed based, in part, on an unrealistic expectation that advocates could influence the availability of suitable placements, reducing discharge delays for in-patients. As decision-makers with experience of working with IMCAs reported, these expectations were not always fulfilled. The impact of this finding on their relationships with advocates is not yet known. In relation to SMT decisions, however, the starting point for health care decision-makers was that advocacy was unnecessary, since clinicians felt that they were already able to establish and represent the views of patients lacking decision-making capacity. Given that the advocates did not have medical training, their input was also viewed as irrelevant. As far as we could ascertain, this attitude was modified by experience of working with IMCAs, but whether such a change of stance takes place generally, as the MCA is introduced, is, again, an issue that needs further exploration. The findings suggested that referrals relating to SMT decisions came from a wide range of hospital wards, not simply from those areas such as old-age

medicine, neurology and intensive care, where high rates of 'impairment of, or disturbance in the functioning of, mind or brain' (section 2(i) of the MCA) might be expected. It is crucial that all health care practitioners, regardless of their specialty, are aware of their duties under the MCA and its Code of Practice, and are appropriately trained.

Some of this training needs to be focused on assessment. Health care practitioners reported feeling confident about assessments but their comments suggested that they considered a status approach to be appropriate, based on diagnosis or scores on a particular clinical test, rather than a decision-specific functional approach (see also [Suto *et al.*, 2002](#), for a similar finding in respect of financial decision-making). Our findings indicated that training in assessment is also needed for social care decision-makers. As a group, they expressed great concern about their ability to assess capacity and were significantly more likely to turn to health care practitioners, normally psychology or psychiatry, rather than use their own judgement.

During the period of the evaluation, the number of eligible referrals made was significantly smaller than had been anticipated by the Department of Health ([Department of Health, 2005](#)), and a large proportion of referrals were ineligible. These findings are probably attributable to the pilot nature of the IMCA service, reflecting limited awareness of the impending legislation. It was not possible to monitor whether all those who were eligible were being referred. Given the misunderstandings we have highlighted, it is plausible that there was limited understanding, at least among some decision-makers, of other aspects of the MCA.

One outcome of the discussions that took place as part of the evaluation is that the Draft Code of Practice ([Department for Constitutional Affairs, 2006](#)), which was in use during the operation of the pilot IMCA schemes, was refined. Under the Mental Capacity Act Code of Practice, introduced in April 2007, decision-makers should not necessarily declare family or friends as not 'practical or appropriate' to consult because they disagree with each other or the decision maker (para. 5.63), or have a 'conflict of interest' (para. 5.67); an IMCA is not required under these circumstances. Rather, the decision-maker has a responsibility to consult family and friends and to arrive at a decision about the person's best interests (para. 5.67), obtaining support from a general advocate to resolve any difficulties (para. 5.68). The impact of this change on the pattern of referrals to IMCAs and, more broadly, on general advocacy services needs to be monitored and evaluated, particularly in relation to CoA decisions, where one-fifth of family and friends were judged 'inappropriate' because of a 'conflict of interest'.

Conclusion

The MCA and its Code of Practice describe the process by which substitute decisions should be made on behalf of adults judged to lack capacity to

make one or more decisions for themselves. This model differs radically from guardianship and, potentially, may transform the way in which substitute decision-making is practised. What our evaluation demonstrates is that applying such a framework to these potentially life-changing decisions in health and social care is far from straightforward. It will be some time before we can tell whether the MCA's ambitions both to empower, as far as possible, and protect adults who lack capacity are fulfilled.

Nevertheless, we can already identify four key issues that are crucial in ensuring that the MCA's focus on the *how* of substitute decision making and the role of IMCAs as safeguards of that process is a success.

First, the basis of the service needs to be kept under review. By excluding men and women with family and friends, it is assumed that the best interests of a person lacking capacity can be adequately represented by those whom he or she knows. This may not be so, particularly in relation to CoA decisions. These can involve complicated issues, such as the client's assessed needs, local funding criteria and the local availability of appropriate residential places. An experienced advocate working as an IMCA may well be better placed to represent someone through this process than a family member or friend for whom this is an exceptional experience.

Second, competent IMCA advocates are required. The new National Advocacy Qualification, funded by the Department of Health, should play a key role both in promoting an understanding of 'the IMCA role' as decision-specific and time-limited statutory advocacy and in providing a framework for evaluating the performance of IMCAs. A formal qualification may also enhance the confidence of IMCAs, particularly in working with medical decision-makers.

Third, decision-makers in health and social care need to fulfil their statutory duties. They must be willing both to refer eligible adults to IMCA services *and* to involve IMCAs fully in the decision-making process. It is important that, for example, IMCAs are kept informed of relevant developments relating to their clients and that their reports are acknowledged and, where appropriate, receive a response.

Lastly, the independence of statutory advocacy needs to be maintained. When an IMCA believes that a proposed decision is not in the best interests of his or her client, a formal challenge should be made to the decision-maker. Our findings provide little evidence of such challenges. However, this does not mean that IMCAs are not fulfilling their function. By providing information about the client's wishes, interests and values, by offering information from others interested in his or her welfare and by considering alternative options, the IMCA is, in effect, 'challenging' the decision-maker to consider what is in the person's best interests. Indeed, the extent to which IMCAs engage in this process with decision-makers, rather than the number of formal challenges they make, may be a very important measure of their performance. There is also a broader issue. In England, IMCA service provider organisations are commissioned by local

authorities, the very bodies responsible for, and involved in, many of the CoA decisions for which men and women who lack capacity are referred. This arrangement must not be allowed to compromise IMCAs' independence when representing a client's interests to a decision-maker.

While aiming to protect the best interests of adults lacking decision-making capacity, the MCA's introduction of the first statutory advocacy service in England and Wales will inevitably change the nature of advocacy. Once marked by its independence from, and challenging stance towards, local authorities, advocacy is gradually being drawn into the decision-making process. IMCAs are trailblazing a future in which advocates will increasingly be called upon to work alongside practitioners in health and social care practitioners. Ultimately, the success of the new IMCA service may lie in the hands of these health and social care practitioners and their willingness to work with an IMCA when making life-changing decisions on behalf of adults lacking decision-making capacity.

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Note

1. Subsequently, discretionary powers were granted to enable IMCAs to be available in certain other situations (see the Expansion of Role Regulations in England (SI 2006/2883) and Wales (SI 2007/852 (W.77)). Our paper focuses only on the initial obligations, imposed under section 35.

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