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Supported Decision-Making in English legislation

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Selbstbestimmung und Solidarität

Unterstützte Entscheidungsfindung
in der psychiatrischen Praxis

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The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is said to introduce a ›new paradigm‹ into the law relating to disability, including mental disability. To that end, Article 12, buttressed by the first General Comment of the CRPD Committee (United Nations 2014), exhorts States Parties to adopt systems of supported decision-making, and to move away from systems based on mental capacity and on the appointment of formal guardians making ›best interests‹ decisions. While this shift is desirable, the transition to it will not happen overnight. Even when there is political will for reform, legislative reform can be a slow process, particularly where, as here, there are few if any legislative models for a CRPD compliant system. Where political will is absent, any legislative reform at all becomes unlikely. Service users, advocates and civil society organizations will in this circumstance have to make the best of the legislation we have.

That in turn means that we must look to the possibilities of our existing legislation. This chapter explores that possibility, using the English Mental Capacity Act 2005 (hereafter the ›MCA‹) as a model. The claim here is not that creative interpretation can make the MCA CRPD-compliant: it is and remains capacity-based legislation that grew out of the so-called ›old‹ paradigm. The suggestion is instead that progress can be made towards some of the CRPD goals within the scope of the present legislation.

The MCA

In short, the MCA takes effect when an individual (called ›P‹ in the statute – a convention continued in the present paper) is unable by reason of an impairment or disturbance in functioning of the mind or brain to understand the information relevant to a decision, retain that information for at least a short time, use and weigh the information to reach a decision, and communicate the decision: MCA, s 2(1), 3(1). When that occurs, events may proceed in P's ›best interests‹, a term defined in the statute and including elements of both objective best interests and (as will be discussed further below) the wishes and feelings, beliefs and values of P: MCA, s 4. Normally, and particularly for decisions relating to personal welfare, matters proceed on that basis without resort to formal

court proceedings: the person in charge of the situation (for example, the doctor if it is an issue of medical treatment) considers whether P has capacity under the terms of the Act, and if P does not, applies the test and proceeds. In cases of doubt, court applications can be made, and if required, the court can appoint a person to make decisions where P lacks capacity (a procedure used most frequently for financial affairs). P can also, when competent to do so, sign a power of attorney determining who will make decisions for P in the event of incapacity. Even in those cases, if P has capacity to make a decision, he or she can make it; and if P cannot make the decision, the best interest test virtually always applies.

Already, there are some elements here that point towards alignment of the MCA with the CRPD. The MCA does not formally determine whether a person with disabilities has the legal authority to make a decision; instead it allows decisions to be taken on P's behalf, when the criteria in the Act are met. There is now no mechanism in English law to ›declare‹ P to be lacking capacity either in toto or for categories of decision in a way that removes rights prospectively. Instead, the legal effect of P's decision is determined by the law related to that decision. Thus for example if P signs a contract, it will be valid unless P was unable to understand its terms and the other party knew of P's inability to understand – a test drawn from the general law of contract. Even then, if P lacks capacity under the terms of the MCA, the contract may nonetheless be valid, if the MCA best interests test was applied and is met.

This still of course does not meet the CRPD Committee's interpretation of CRPD compliance: capacity is still very much a part of the law. Elements of the MCA structure do provide the potential to require enhanced supported decision-making, however, allowing for some engagement with the ethos of the CRPD. The overarching principles in the Act include the following:

1(3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

In determining capacity, it is sufficient that P understands the information relevant to the decision if ›he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or other means)‹, and communication of the decision may be by way of ›talking, using sign language or any other means: MCA, s 3(2),(3).

If an individual lacks capacity to make a decision, the best interests test requires the person applying the test ›so far as reasonably practicable, [to] permit and encourage [P] to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him‹: MCA, s 4(4). The person applying the test must also consider, ›so far as is reasonably ascertainable‹,

- a. P's past and present wishes and feelings;
- b. The beliefs and values that would be likely to influence P's decision if P had capacity; and
- c. The other factors that P would be likely to consider if he were able to do so (MCA, s 4(6))

Carers and similar people are to be consulted as to issues (a) to (c): MCA, s 4(7). For serious decisions, advocates are to be provided for P when there is no appropriate family member or carer to be consulted: MCA, s 35-41.

Viewed collectively, this gives a strong steer that supported decision-making is to be expected both in the assisting P to reach a competent decision when that can be achieved, and if P is found to lack capacity, in ensuring that P is as involved as possible in how events proceed and that his or her wishes, feelings values and preferences are a significant factor in the decision taken. This is consistent with the Code of Practice published pursuant to the MCA, which includes an entire chapter on ›How should people be helped to make their own decisions?‹ (United Kingdom 2007).

There is clearly much here for proponents of supported decision-making to work with. Indeed, the statutory language is in place for support to have a pivotal role in the MCA system. So far, it is doubtful whether this potential has been realised. This paper now turns to explore that.

What is actually happening out there?

The implementation of the MCA was considered by an ad hoc committee of the House of Lords in 2014. The report was not encouraging. The Committee concluded that the supported decision-making envisaged by the MCA was not in fact happening. Instead, the evidence to the Committee was that the MCA was perceived as a framework for making

decisions for people lacking capacity in ways that often excluded P and his or her family carers, rather than encouraging P and maximizing P's participation in decision-making (United Kingdom 2014, para 79). The Committee cited limited resources and insufficient professional education by way of explaining this failure.

The Committee's view focuses implicitly on the failure by professionals to provide support, but hints of similar views can be found about support provided by families. In *Public Guardian v PM*, a case concerning the suitability of an appointee under a power of attorney, Senior Judge Lush noted that the appointee in question made a point of giving P time to and support to reach decisions, noting ›[t]his is commendable conduct and, in my experience, it is unusual to find an attorney attaching such prominence to it in practice.« (*Public Guardian v PM*, para 45).

It is difficult to know whether practice is actually as poor as these views suggest. Senior Judge Lush is extremely experienced and his assessment is to be accorded considerable weight, but courts tend to see cases of conflict, often bringing out the worst in the litigants. The picture outside court may therefore be better than his comment suggests, but good data are hard to find. A 2015 systematic review of the literature about the implementation of the MCA by Hinsliff-Smith and colleagues cites no paper in which supported decision-making was the primary subject of consideration. (HINSLIFF-SMITH 2015). Instead, the focus of the literature seems to be the degree to which the statutory mechanisms – powers of attorney, advance planning and the like – are understood, rather than what support for decision-making people need to make practical and effective use of those mechanisms, and to be involved in decision-making on an ongoing basis. That is not inconsistent with a pessimistic view of the role of supported decision-making in current MCA practice, as it may well be that if there were a lively culture of support out there, it would be reflected to some degree in the academic literature. The absence of that literature is thus not encouraging. That is nonetheless an argument from silence: the reality is that there is not an evidence base in the academic literature as to what support is in fact happening, and, at least in a general sense, what mechanisms of support are found to be helpful.

One of the difficulties in the development of the literature may be that there appears to be no established definition of what support for decision-making actually means. As other papers in this volume no doubt

discuss, it might mean the work of families to assist their loved ones, services provided by advocacy professionals, professional care providers working to assist P to reach decisions relevant to the care that professional is providing, or much broader programmes such as educational or formalized training provision to assist people of limited abilities to learn to understand material relevant to making decisions. A given individual may well be caught up in a number of these, and disaggregating them for study purposes may well be a complex task.

If the views of the House of Lords Committee and Senior Judge Lush are right, what needs to happen is a cultural change in the way the MCA is understood. The next section of this paper will consider that question by looking at the approach of the Court of Protection, the court charged with the interpretation of the MCA, to supported decision-making. The logic behind this choice is partly principled: the Court has a particular role and ideological cachet in the understanding of the MCA and determining the expectations for its implementation. It thus has a pivotal role in introducing the cultural change. It is also partly practical. The Court's reasons for judgment are public, and a large number are available through standard legal research databases. It is therefore possible to acquire a sense of what the court is doing in this area, in ways that are much more difficult in other contexts such as supported decision-making within families.

The Court of Protection and Supported Decision-Making

P's Wishes and Feelings, Beliefs and Values It would be fair to say that the Court did not start out well from the perspective of supported decision-making in its interpretation of the MCA. An early and influential court decision, *MM, A Local Authority v MM and KM*, held that there was 'no relevant distinction' between the best interests test in the MCA and the purely objective test of best interests that predated it (*MM*, para 92). This previous test had no express requirement that P be involved in the decision, nor that P's wishes and feelings be considered, and following *MM*, it is perhaps unsurprising that for a number of years, P's wishes and feelings, beliefs and values were often not even recorded

in the Court's decisions, let alone accorded a significant weight in decision-making. When judges did give significant weight to P's views, they might be subject to criticism on appeal (see, eg., *Re M*; *ITW v Z and M*, para 35), and it was rare indeed that the views of P were pivotal to the decision reached as to what his or her 'best interests' were.

On this, the Court does appear to have changed in recent years. This may in part flow from a variety of non-legislative documents. The House of Lords report, noted above, spoke strongly in favour of an enhanced role for P's wishes and feelings (United Kingdom 2014, eg at para 104), and in a report on potential revisions to legislation for people lacking capacity deprived of their liberty, the Law Commission also argued that the MCA best interests test should be amended so that P's wishes and feelings should be assumed to be determinative of his or her best interests unless there is good reason to depart from the assumption (Law Commission, 2016 para 12.2; 2017 chapter 14). Further, there is evidence that the CRPD, with its reference to will and preference, has jostled the Court's approach (see, eg., *Wye Valley NHS Trust v B*). The Court's approach thus a renewed emphasis on P's will and preferences in the general policy arena.

Perhaps more significantly, there is new appellate litigation. The Supreme Court, in *Aintree University Hospitals NHS Trust v James* did not in so many words impress the relevance of P's wishes and feelings to the exclusion of other elements of the best interests test, but it did exhort courts and decision-makers to consider matters from the perspective of P:

The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be. [para 39]

Whatever the reason, it is now routine that the wishes and feelings of P are noted in the judgment, and discussed as part of the process of decision-making. And it does seem that the Court is increasingly taking them seriously, at least in matters relating to personal care.

This increased prominence of P's wishes and feelings, values and beliefs is a very encouraging development. First, it shows that courts can actually change their practice in line with developments in disability policy. Certainly, the statutory language was in place for them to do so; but the fact remains that they have done so. For advocates hoping to use existing statutory language to build an enhanced legal structure for supported decision-making, that is notable and important: if the courts are on side, this can be done. It is also important, of course, for substantive reasons: P's wishes and feelings, values and beliefs are now a central part of the decision-making process, and that is a substantial move towards the values of the CRPD.

At least two caveats are important, however. The first is that, while P's views are now being taken seriously by the Court, they are not always followed: there is still no shortage of cases where the wishes and feelings of P are overruled by the courts, and P is for example deprived of liberty, treated without consent, or deprived of access to loved ones in contravention of his or her wishes. That is no doubt in part the result of the statutory structure, where P's wishes and feelings are not the only element to be considered in determining best interests. It is a reminder that while the Court may be moving toward CRPD values, the MCA is still not CRPD-compliant.

Second, the changed practice is most apparent in the realm of personal decision-making. P's wishes and feelings may have an impact in decisions taken as to who will make property and affairs decisions for P, but it is much less obvious that P's wishes and feelings, values and beliefs are taken into account for example in deciding what investments should be bought in P's name. There is no statutory reason for this discrepancy: the relevant provisions are the same for all decisions taken when P lacks capacity. They are instead probably historical. Prior to the MCA, the property and affairs of a person lacking capacity were administered by the state (albeit through intermediaries, often family members), and P's views had no express place in how that was done. It seems likely that this mentality has continued into the new statutory structure. The role of P in these decisions does not seem to have been the subject of litigation; it remains to be seen how that will be resolved, if and when it is.

While some progress has been made in increasing the prominence of P's wishes, feelings, values and beliefs in decision-making as to how decisions are to be taken, it is less clear that the court has made comparable

progress in promoting the systems of support needed to buttress and animate P's wishes and feelings. While the Court is concerned about what P's wishes are, it has not developed sophisticated ways of exploring how those views were arrived at, whether adequate and appropriate support has been offered to reach those views, and how to understand the relationships between P and those around him or her in the provision of supported decision-making.

The court is, of course, concerned about ensuring that appropriate services are received by P, for example through the development of appropriate care plans. Usually, social services or similar staff are at the core of the design and implementation of these plans. Often, they appear to be of a primarily programmatic nature – provision of practical support for community living, for example - but sometimes, they can be relevant to the support and development of decision-making. A Local Authority v TZ (No 2) for example involved a twenty-four-year-old gay man with learning disabilities, who wished to experience some of adolescent gay life, including meeting other men for sexual experiences. The Court's view was that he had capacity to consent to the sexual behaviour, but needed support in understanding how to navigate the gay scene and making safe choices regarding whom to be sexually active with, and how to approach them. The social services team was duly dispatched to provide assistance to him on these issues including, at least initially, accompanying him in his forays onto the gay scene. Failure to provide this sort of support programme can have consequences. In CH v A Metropolitan Borough Council, for example, a man required sexual education prior to having sexual relations with his wife. Failure to provide that programme for fifteen months resulted in the social services authority paying him £10,000 in damages, plus legal costs of more than £7,000. This suggests that there may be legal expectations that support be provided, at least when it is prerequisite to the exercise of ECHR rights.

The TZ example nicely illustrates a number of tensions and ambiguities in the Court's view of support. First is the question of whether support is about assisting TZ to articulate his own preferences (supported decision-making as envisaged by the CRPD), or whether it is about ensuring that TZ makes choices with 'good' outcomes (a vision focused more on objective best interests). Second, and perhaps related, is the question of the relationship between the providers of the support and P. It is hard to imagine that the support being offered will be morally neutral. TZ

is a particularly clear example of this (who is an ›appropriate‹ person for TZ to have sex with?), but values will enter many if not all of the decisions on which support is sought.

This latter difficulty arises whether the support is part of a programmatic intervention or instead a less formal support process, such as the ongoing day-to-day support for sometimes fairly routine decision-making: relationships between the supporter and the supported can be complex, and in the context of support for decision-making, the Court has barely begun to engage with the complexity of those relationships. The Court is of course a court, and consistent with that tends to view the parties through a legal lens that considers individuals as separate and autonomous actors. The desire seems to be to distil out P's views, hermetically sealed from the views of those around them. That can result in support being removed from P at precisely the time it is needed. Thus the Court notes the following regarding the support offered to P in his interview by a Court-appointed expert psychiatrist, a pivotal witness, in assessing his capacity to make decisions on where he would live, and whether he would be deprived of liberty in a care home. The RPR (›relevant person's representative‹) is an individual appointed through the MCA specifically to support P in matters related to deprivation of liberty:

Dr Layton spent 3 hours with MB who was supported by his RPR. Her presence and involvement in the assessment was neutral as far as I can see apart from an attempt to prompt MB with an answer early in the interview which was prevented by Dr Layton. (MB v SCC, para 9)

The question here is how far the required ›neutrality‹ of the supporter, who presumably knows P, limits the support given. This question is particularly complex in the case of family members, where the supporter may have been in a relationship with P for decades, and may have consequent understanding of how P communicates, or how to help P articulate his or her wishes and feelings, values and beliefs. The attempt to ensure the purity of P's views can result in important support for P being actively denied. Hillingdon v Neary provides a further, perhaps more extreme example, where the refusal of the expert to allow the father's interpretation of his disabled son's communication effectively silenced the son. Unusually, the court was critical of this in the Neary case.

Where the Court does consider the relationship between P and family members and similar carers in a decision-making context, it is often with a view to perceived undue influence by the supporter. The Court is right

to have real concerns here, but the obvious question is when influence becomes ›undue‹. *A Local Authority v A* is a particularly clear example. Both Mr and Mrs A had learning difficulties. It seems that Mr A wanted children; Mrs A was more ambivalent. Mr A clearly had some power advantages in the relationship: he owned the matrimonial home, for example, and there was some evidence that Mrs A believed wives should defer to their husbands, at least to some degree. She did, according to at least some of the evidence, want children. The question for the Court was whether Mrs A had the capacity to decide on contraception, and if not, how the Court should proceed, and at issue was whether Mr A was exercising undue influence over his wife. The question as regards the present chapter is whether we understand his involvement as ›undue influence‹: in many (most?) relationships contraception is likely to be a decision involving the views of both parties, even if in law it is a choice of only the person taking the contraceptive intervention. What makes this case different? Indeed, could Mr A have understood his actions as supporting his wife's decision-making? And if that was in some sense qualitatively poor support, what makes it so? The Court has not (and, indeed, the scholarly literature has not) developed theoretically or pragmatically robust ways of exploring these relationships that lead to helpful insights about the nature or quality of the supported decision-making in question. Certainly, it seems wrong to decouple the contraception decision from the complexity of the relationship as a whole; but beyond that there is a void in the understanding of how to approach ›support‹ when provided in the context of ongoing and intensive relationships.

This question of understanding the relationship at the basis of the support extends not merely to family members. In *A Local Authority v A*, the Court ordered that support be given to Mrs A to determine her views, free from Mr A. That support would be provided by social services. Here again, the question of the relationship between P and the supporter arises. One thing that was clear from the case was that there was no trust between Mr A and social services, and quite possibly not much between Mrs A and social services. It is at best questionable whether support can work in that situation, and that is before the TZ questions are asked about whether the professional supporters can realistically approach the situation in a morally neutral way. That is of particular concern, given that one of the objectives of the CRPD is to move away from ›medical‹ and other professionalised models of disability. If that

is to be taken seriously, then ›professional‹ values brought to support must be viewed with healthy scepticism. It might further be remembered that the relations between P and social services are also likely to be unbalanced, with social services exercising significant power over P. It is notable that the undue influence of professionals in these support relationships is never mentioned by the courts.

All of this suggests that moving beyond mere ›wishes and feelings‹ to a requirement that real supported decision-making be provided will be a challenging move for the Courts and for advocates: much more sophisticated ways of understanding the personal relationships behind the processes of supported decision-making need to be developed. That is not a unique problem to the MCA system: the CRPD literature has been asking for some time how we should understand supported decision-making and the personal relationships around it. Until some clarity on that is attained, it is difficult to see long-term developments should be taken forward; but it might be a good start for the Court to ask more probingly what processes were used to arrive at the articulation of P's wishes and feelings, and by whom.

Conclusion

In much of the world, there appears to be little appetite for legislative reform on matters of capacity. That suggests that in the near future, disability rights advocates will have to work with the legislation we have. The English experience shows that there is the possibility for forward movement through the actions of courts even without statutory reform, when the courts understand the desirability of doing so.

That leaves the question of what we want the courts to do. Certainly, and consistent with the CRPD, an enhanced role for the will and preferences of the person with disability is desirable, and certainly, an enhanced role for the court is desirable in determining that these will and preferences are reached based where necessary on robust and appropriate supported decision-making. More problematic is determining how we want the courts to exercise that role: we at this point seem to have little to offer on what the court should look at to decide whether supported decision-making has been necessary, robust and appropriate.

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