

Inclusion London

Supporting London's Deaf and
Disabled People's Organisations

The Mental Capacity Legislation and Our Human Rights; the voice of Disabled people, their organisations and advocates

**Written by Gillian Loomes
Commissioned by Inclusion London**

About this report

This report was written by Gillian Loomes – a researcher at Leeds University with specific interests in voice, especially in the context of mental capacity.

Inclusion London commissioned this research report to obtain independent analysis of the views expressed by Disabled people, Disabled People’s Organisations (DPOs) and professionals about the proposed changes to the Mental Capacity Act 2005.

We included data from:

- **An easy read survey developed jointly by 39 Essex Chambers, Dr Lucy Series from Cardiff University School of Law and Politics and CHANGE,**
- **A consultation event and additional interviews with DPOs and people with learning difficulties held jointly by Inclusion London and People First Self-Advocacy.**

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Executive Summary

The Mental Capacity (Amendment) Bill represents an opportunity to reform the Mental Capacity Act 2005 (the MCA 2005): a piece of legislation that has received significant criticism because of its complexity, the bureaucratic strain that it places on institutions and services that operate under its framework as well as the tensions between the MCA 2005 and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

This report presents the views of Disabled self-advocates, alongside those of non-Disabled supporters on issues arising in the new bill. These issues are presented in four themes: (1) supported decision-making; (2) advocacy; (3) participation; and (4) Deprivation of Liberty. The key findings are as follows:

- Disabled people unequivocally value the right to support to have decision-making autonomy
- There is a strong emotional dimension to supported decision-making for Disabled people
- Advocacy is key to the abilities of Disabled people to access their right to decision-making autonomy
- For Disabled people, advocacy is about being heard, and addressing the power imbalances between people lacking mental capacity, and the institutions and services that support them.
- It's paramount that Disabled people have the right to participate in court proceedings and express their views in their struggle against unsatisfactory or oppressive care when they lack mental capacity, and may be deprived of their liberty.
- Disabled people are extremely concerned about the protection of their right to liberty and advocate for this forcefully. If decisions are to be made regarding the deprivation of their liberty, they demand those involved are people who know them well, and who they trust.

The report also demonstrates that the views of Disabled people and their organisations differ in myriad respects to both their family and friends, and service providers. This indicates the importance of consulting Disabled people and Disabled people's organisations, in line with the principles of the UNCRPD.

Introduction

Mental capacity law presents a range of challenges for all those concerned with disability rights. The Mental Capacity Act 2005 – enshrined into English and Welsh legislation – made some profound encroachments into the lives of people who have disorders of the mind or brain. From a disability rights perspective, there are several fundamental concerns with the framework of law set out in the MCA 2005. Critiques of the MCA 2005 are framed around its perceived failure to comply with international treaty provisions, such as the UNCRPD. In particular, the MCA 2005 adopts a discriminatory position in respect of Disabled people, by providing at s2(1) that in order to be deemed to lack mental capacity, an individual must be experiencing “an impairment of, or a disturbance in the functioning of the mind or brain”. It also fails to give sufficient priority to the wishes and feelings of individuals deemed to lack capacity (Martin et al., 2014).

An aspect of the MCA 2005 that impacts dramatically on the rights of those on whose lives it encroaches is the framework referred to as the Deprivation of Liberty Safeguards (‘DoLs’). Introduced into the MCA 2005 via the Mental Health Act 2007, DoLs have long been criticised as problematic and overly bureaucratic, and, following the impact of case law¹ has been the focus of attempts at legislative and policy reform. It is in the pursuit of these reforms that the Mental Capacity (Amendment) Bill has been drafted.

There has already been consultation with a range of stakeholders concerning the direction of legislative reform within in the bill. Charities, organisations, care homes and institutions that provide services to disabled people – including people who may lack decision-making capacity – have set out their position regarding the bill (see, for example, Dimensions, 2018). However, an issue of huge concern is the lack of apparent consultation with Disabled people and our organisations. The views of Disabled people, including those whose lives are set to be directly and profoundly impacted by the introduction of the proposed legislation, appear not to have been considered. This is a particularly grave concern given the provision in the UNCRPD stating that Disabled people and our organisations should be consulted about

¹ Cheshire West and Cheshire Council v P [2014] UKSC 14, [2014] MHLO 16

the development of legislation and policy, as described in Article 4 of the treaty:

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”

The UN Committee’s recent General Comment 7 clarifies a definition of “representative organisations” confirming: *“They can only be those that are led, directed and governed by persons with disabilities.”*

[Emphasis (United Nations, 2006: 2)]

Throughout the history of the MCA 2005, it has struggled to live up to the standards of the UNCRPD (to which the UK has been a signatory since 2007). This proposed bill has the potential to shift this position, so that English and Welsh mental capacity law may begin to embrace and engage with the standards set by the UNCRPD. In order to do this it is, at very least, imperative that Disabled people and our organisations are directly involved in shaping legislative reform through the Mental Capacity (Amendment) Bill. It is insufficient for our concerns to be replaced by those of informal and formal disability supporters, and other stakeholders who seek to speak for us. While the voices of family members, service providers, clinicians, and others who support individuals who lack decision-making capacity are key to consultation on this bill, they cannot, and should not be interpreted as a proxy for the views of Disabled people and our organisations.

The Report

This report contributes to ongoing consultation on the Mental Capacity (Amendment) Bill, currently going through Parliament, by centering the preferences, wishes, feelings, and beliefs of Disabled people and our organisations. Data obtained through events organised by Disabled People’s Organisations (DPOs) in England along with a survey conducted by the same organisations working together with academics and lawyers.

Methodology

The analysis presented here combines data gathered at a consultation event attended by 25 individuals with learning difficulties and 11 representatives from DPOs as well as responses to a survey (n = 127). Both the event and the survey sought Deaf and Disabled People’s views of the Mental Capacity (Amendment) Bill, as well as the views of DPOs. The survey questions are provided at the end of this report (see Appendix 1). There was considerable overlap between the feedback received at the consultation event and the responses to the consultation. Data has been integrated in order to extract contributions from both sources in the construction of the four major themes relating to bill.

Status of Respondents

The 127 responses to the survey were received from a range of people and organisations. The table below shows a breakdown of the status of the participants:

Status of Respondent	Number of Survey Responses
Unknown	80
Professional (Individual)	16
Professional (Organisation)	14
Self-Advocate (Individual)	10
DPO (Organisation)	4
Family Carer	3

Table 1: Status of survey respondents (in relation to the Mental Capacity (Amendment) Bill

Of the respondents where their status in relation to the Bill was made clear, the majority were professional stakeholders – either responding

individually or as an organisation. These included speech, language, and communication specialists, nurses and allied health professionals, psychiatrists and psychologists, advocacy organisations, and academic researchers. Disabled self-advocates and their organisations also responded to the survey, along with family carers. In the analysis presented in this report, the respondents are divided into two categories – (1) Disabled Self-Advocates (self-advocates and DPOs); and (2) Non-Disabled Supporters (unknown: non-disabled, professional individuals, professional organisations, family carers).

As indicated in the introduction, this report centers the views and concerns of Disabled people and DPOs. It does this in order to enable Disabled people’s concerns to be recognised through the development of this legislation, in a manner envisaged by the UNCRPD. This report presents the views of Disabled people and our organisations alongside those of non-Disabled, informal, and professional supporters. It does this in order to emphasise a key point – **that the views of non-Disabled stakeholders cannot be interpreted as a proxy for those of Disabled people, and that consultations on legislation and policy affecting Disabled people (including those who lack, or may lack capacity) must be accessible to, and engage meaningfully with, Disabled people and our organizations.**

Analysis

The data collected through face-to-face consultation and surveys were analysed across 4 key themes that are central to the Mental Capacity (Amendment) Bill. These are (1) supported decision-making, (2) advocacy, (3) participation and (4) deprivation of liberty. They are followed by discussion and concluding remarks based on the findings.

(1) Supported Decision-Making

Access to supported decision-making is at the heart of the rights secured for disabled people under the CRPD. It is through support for individual decision-making that Disabled people can be assured of their rights to “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (United Nations, 2006: 3). Set out below are the views of Disabled and non-

Disabled respondents concerning rights to supported decision-making for people who lack, or may lack, decision-making capacity. Respondents explained their views on whether people should be given the right in law to say who they want to support them to make decisions, and the circumstances in which they feel someone else should be able to make a decision that is different to what the person wants. Here is what people said:

Disabled Self-Advocates

It was suggested unequivocally that people should be given the right to decide who should support them to make decisions.

“Everyone has the right of making decisions by themselves with support.”

“The best thing is for us to choose who makes the big decisions for us.”

The voice of the person whose decision is being made is vital and being heard is central.

“Professionals might not do their job properly and listen to us.”

Support and accessible information in the decision-making process are crucial. Advocates play a pivotal role in people’s right to supported decision-making, and they must be supported themselves.

“If [we don’t have capacity] we would need the help of an advocate or similar.”

“It’s not fair for both the person lacking capacity, and the advocate that the advocate has to teach themselves about the law and how the system works.”

There was strong emphasis on the importance of the personal qualities of decision-making supporters. Trust in the person is key, along with familiarity between the person whose decision is being made and the supporter.

“It needs to be the right person.”

“We should have people we can trust. Family members, doctors, friends...”

Disabled respondents focused on the emotional impact of support. Being supported by someone known to the person has a positive impact on emotion and avoids discomfort. This is contrasted with negative experiences with professionals.

“You’re happier when you are supported by someone you know rather than a stranger. We don’t want to go back to the days of institutions.”

“...some very difficult experiences with professionals...”

“We have seen people who are supposed to help us play on their phones and not listen to us.”

Notably, there was no mention in the survey responses of people who identified as Disabled of ‘best interests’, or of a belief that their family members were necessarily the most important members of a decision-making support network.

Non-Disabled Supporters

Non-disabled supporters were more equivocal in their responses, about the right to supported decision-making:

“It depends...”

“It depends on the individual’s ability to make this decision”

“Whenever practically possible”

They demonstrated a strong focus on ‘best interests’.

“When individuals do not have capacity I do believe that they will need support with this to ensure that they have chosen someone who will ultimately act in their best interests. This may not be the individual’s person of choice.”

“Someone else should be able to make a decision that is different to that which a person wants.”

There was an emphasis on the vulnerability of people lacking the capacity to make decisions for themselves.

“It would be helpful to have a safeguard whereby a vulnerable individual is protected from this potential abuse of power.”

There was also some concern that an individual who lacks, or may lack the mental capacity to make specific decisions may also be at risk in terms of identifying someone to make decisions on their behalf:

“Once a person lacks capacity, they may struggle to identify who is a suitable representative.”

This focus on individual vulnerability is also demonstrated by the concern that people lacking capacity:

“Could be targeted by someone who does not necessarily have their best interests at heart.”

And

“People who spend more hours with the person may have their own agenda.”

“Professionals have their own best interests at heart.”

For some non-Disabled respondents, a distrust of professionals also led to the suggestion that family members have a particular role in decision-making on behalf of individuals who lack mental capacity:

“E.g. parents or sons/daughters should have the absolute right to support the person to make decisions. Not these professionals.”

“Because family members know best of their loved ones and hold their best interests in their hearts.”

Key Points

For Disabled respondents, the right to be supported to make their own decisions is unequivocal. Their responses demonstrate a strong attachment to this right. They also describe the qualities they consider important in those supporting them to make decisions, with these being based heavily around trust. Their responses also emphasize the emotional impact of supported decision-making, and remind us of what is at stake in supporting people to access decision-making autonomy in their life.

The contrast presented in the responses of non-Disabled supporters is of concern. In particular, the degree to which they represent equivocation

regarding the rights of individuals to access decision-making autonomy is problematic, given the emotional impact that Disabled respondents indicate such autonomy to cause. Likewise, the focus on vulnerability, and the suggestion that the right to support for decision-making autonomy is contingent on the individual abilities of the person involved are extremely concerning.

Further, given that there seem to be distinct differences in the approaches of Disabled people and supporters to decision-making, autonomy, and supported decision-making, the suggestion that family members should be unquestioningly prioritised as decision-making supporters for Disabled people who lack capacity, is notable.

Recommendations

- **'Best interests' tests should be changed to give more weight to person's wishes and feelings.**
- **Individuals should be given a legal right to choose and nominate a person who will support them to make decisions**
- **When it comes to decisions that have an impact on people's human rights, such as deprivation of liberty, restrictions of contact or medical treatment, professionals should be required to demonstrate the support they tried to provide to enable the individual to make the decision for themselves and explain why this support did not work.**

(2) Advocacy

Advocacy is central to the needs of people who lack or may lack decision-making capacity. It is the pivotal way in which people's views, wishes, feelings, and beliefs are represented, and their rights are upheld. The significance of advocacy was evidenced in the introduction of statutory advocacy through the Mental Capacity Act 2005. However, the draft Mental Capacity (Amendment) Bill raises some issues about access to advocacy. Our survey asked respondents for their views on when people need access to advocacy and how an advocate should assist people in making complaints about their care. This is what people said:

Disabled Self-Advocates

Advocacy should be easily available to everyone lacking capacity to make decisions in their lives.

“Everyone coming into the care system must have a right to an advocate.”

“Anyone may need an advocate to support them at some time in their life.”

Advocacy is crucial in addressing the power imbalances experienced by people who lack or may lack decision-making capacity.

“There is an imbalance of power between the state and persons being cared for by the state, which often leaves service users feeling very disempowered.”

“Everyone has the potential of having their liberty taken away by the state.”

The most important aspects of the advocate’s role is to listen to the person, help them to understand their rights, to speak out for them to relevant authorities, and to engage with complaints procedures if necessary.

“Advocates should listen to the person and help them.”

“Advocates should speak out for me about my care and complaints.”

“Advocates should talk to other people who provide the care to make things better.”

“Advocates should listen to me and help me find a solution to make things better, and talk with my care provider.”

An advocate for me is:

- “Someone who I trust”
- “Someone who will fight my corner, who is on my side”
- “Someone who is independent”
- “Someone who knows me or takes time to get to know me”
- “Someone who is able to support and listen”

- “Someone who knows the law and knows what steps to take”

Non-Disabled Supporters

Advocates are seen as proxy decision-makers in the absence of family members.

“People who have no family to make those decisions should have access to an advocate.”

“Advocacy is more important if they have no family/ next of kin who can help make best interests decisions.”

There is a strong emphasis on ‘best interests’ in advocacy

“Individuals who have no families or friends acting in their best interests need access to advocacy.”

“Vulnerable people who may not have someone looking out for *their* best interests need access to advocacy.”

In some instances, the role of advocate was understood as being that of a quasi fact-checker, or independent assessor to investigate the validity of people’s complaints:

“Advocates should consider if the complaint is justified and suggests a problem with their care. If they believe the person has a reasonable complaint, it should be raised with the care home manager, and, if necessary, escalated to the Local Authority.”

“People should always have the right to go to court and tell the judge what they think about their care if, following assessment by an independent advocate, there is sufficient evidence that the care being provided is inappropriate. Bearing in mind that many people in this group would have limited capacity to make those kind of judgments, it is essential that an independent person with the necessary skills and knowledge can examine the facts of the issue and recommend whether it should go to court or not.”

Non-Disabled respondents focused considerably on the individual impairments and other challenges experienced by people lacking capacity as being a key reason for advocacy involvement:

“People who struggle to speak up for themselves” should have access to advocacy.

“People assessed as not having capacity” should have access to advocacy.

“People who have specific communication difficulties which need specialist input to ensure their voice is heard” need access to advocacy.

Access to training and support for advocates was seen as important:

“The advocate needs to be fully and adequately experienced in working with the client group involved.”

Advocates should “have training in communication and have back-up themselves because they will also need support.”

Some non-Disabled supporters also shared the views of the Disabled respondents, that advocacy should be widely available and should be about listening to people and helping them communicate their views:

“People who struggle to speak up for themselves” should have access to advocacy and “this should always be offered, not only if someone complains.”

“Advocates should ensure that the individual’s voice is heard, and is central to all discussions.”

Key Points

There is widespread support for advocacy as a way of ensuring that people lacking the capacity to make decisions are heard, and their rights are respected. However, it is very concerning that some of those supporting people lacking capacity (either formally or informally) seem to fundamentally misunderstand the nature of advocacy. It is not the role of the advocate to assess the validity of a person’s complaint. It is very worrying to think that Disabled people who lack the capacity to make key decisions in their lives, may be reliant on people who do not understand the nature of advocacy in order to access such a key service.

The draft Mental Capacity (Amendment) Bill makes access to advocacy dependent on capacity and best interests tests. Disabled self-advocates are clear, they should have unrestricted access to advocacy, except situations when they actively do not want this support or they are happy

with a relative or another person in their life to be their advocate. It is therefore imperative that all those who support Disabled people have a clear understanding of advocacy, in terms of (1) when people lacking capacity should have access to advocacy and (2) the role of advocates in supporting people to understand their situation, their rights, to be involved in the process and to make complaints regarding their care. This has to be the joint responsibility of the advocacy sector and all those providing both informal and formal support to disabled people who lack, or may lack decision-making capacity.

Recommendations

- **Best interests test should be removed from advocacy provisions and advocate should be appointed for every individual when responsible body believes the advocacy support is necessary to help person participate in the process of decision-making, to understand their rights and to exercise the right to challenge deprivation of liberty.**
- **Requests for advocacy support should not be subject to capacity or best interests tests. Individuals should be able to have an advocate of their choice.**
- **Individuals should have access to advocacy not only after the decision is taken but also during the assessment to ensure their voice is heard and they understand their rights and the process.**
- **The role of an “appropriate person” should be clarified to ensure the appropriate person is willing and able to exercise this role and the individual who they are representing is happy with this.**

(3) Participation

As indicated above, the participation of Disabled people in the development of legislation and policies that impact their lives is a central part of the UNCRPD. It is also at the heart of reform of the Court of Protection – a key institution for the implementation of the MCA 2005, with procedural rules for the court having created increased opportunities for the participation in proceedings of individuals lacking

capacity, in whose best interests the court makes decisions. Here are the views of disabled people, and our non-disabled supporters regarding the participation of people lacking mental capacity in court proceedings.

Disabled Self-Advocates

There was indication of a strong desire among Disabled people to be able to participate in court proceedings and tell the judge of their wishes and feelings, with the suggestion that people should be able to participate in court:

“When they need to.”

And the argument that :

“People with learning disabilities and autism should have the same rights as everyone else and to have the right support around going to court.”

There was also a considerable association of the right to participate in court with the experience of problems or feelings of discomfort or dissatisfaction. It was felt people should be able to participate at court:

“When you have been hurt or abused because we need to make sure things like that should never happen again.”

“When the care is against my wishes and needs.”

“When I have a major problem like I’m not doing the things I want to do.”

“When people don’t listen to my complaint and nothing is resolved.”

Non-Disabled Supporters

There was also a tendency among non-Disabled respondents to associate the right to participate in court, and share views, with dissatisfaction or complaint, such that people lacking capacity should go to court:

“If they feel their complaints have not been addressed and there are ongoing issues.”

“In the event of a serious complaint or malpractice.”

“If attempts to raise concerns and make a complaint have had undesired or unhelpful outcomes and the individual or their advocate continue to have concerns.”

There was also an association between the right to participate in court and the gravity of the decision being made, such as the suggestion that people should have the right to participate:

“When it relates to serious decisions.”

Worryingly, there was also an indication of gate-keeping among non-Disabled supporters, concerning who should participate in court proceedings, with people possibly only participating:

“If they have capacity”

Or

“When their claims are corroborated by their advocates and there is evidence that something serious is wrong and needs correcting.”

There was, however, also evidence among some non-Disabled respondents of a focus on equality, and particularly the right of equal access and participation, as:

“Anyone complaining about their care should have the right to go to court.”

“They should have the same rights as everybody else.”

“People who lack capacity are citizens just like everyone else. They should have access to the same rights, and the judiciary at any time, just like other citizens.”

Key Points

Participation in court proceedings clearly represents for the Disabled respondents an avenue through which they can share their grievances and address issues of difficulty or oppression. For this reason, it is problematic that there seems to be a tendency among non-Disabled supporters to restrict court participation, by reference either to the abilities of the individual, or the nature of the matter before the court. It is incredibly important that non-Disabled supporters of those who lack capacity and find themselves involved in court proceedings understand

the fundamental significance of court participation as an avenue for self-advocacy for people lacking mental capacity.

Recommendations

- **Individuals and those concerned with their welfare should be given information about their rights in an accessible way before any steps to deprive them of their liberty are taken or any decisions which will have an impact on their human rights are made;**
- **Responsible bodies and Approved Mental Capacity Professionals should have a duty to consider referring the case to the Court of Protection.**
- **Civil procedure rules should be changed to include a presumption that the person concerned should give evidence in proceedings unless all parties agree this would not be in their best interests.**
- **The court of protection should be resourced to make all necessary reasonable adjustments in proceedings to ensure individuals concerned can participate as fully as possible.**

(4) Deprivation of Liberty

Perhaps the most significant aspect of mental capacity law impacted by the bill is that of deprivation of liberty – currently governed by the Deprivation of Liberty Safeguards (DoLS). As explained in the introduction to this report, the DoLS framework has received considerable criticism in policy and case-law and has been acknowledged as placing an overwhelming bureaucratic burden on local authorities and the Court of Protection.

Among the changes proposed in the bill, through the introduction of what will be called the ‘Liberty Protection Safeguards’, are some particularly concerning amendments, notably: it will become possible to apply for an authorisation of deprivation of liberty in any setting (currently DoLS apply only in care homes or hospitals). The bill proposes

two alternative processes, with either care home managers or Local Authorities, Clinical Commissioning Groups, or hospital managers responsible for deciding whether to commission an independent assessment of the deprivation of liberty, and whether it is in the best interests of the person lacking capacity to have access to an independent advocate.

There are several concerns about these proposals, particularly in terms of their compliance with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): Article 14 of which states that no one should be deprived of their liberty because of their disability and, according to Article 19 of which Disabled people should have support to live in the community, and can't be forced to live in a particular setting. Furthermore, in 2017 the concluding observations of the UN Committee to the UK government recommended the repeal of legislation and practices that authorise non-consensual, involuntary, or compulsory detention or treatment of Disabled people, on the basis of actual or perceived impairment.

The bill is not aimed to enhance and promote person's liberty, it is based on the assumption that it is ok to deprive people of their liberty when they have a mental disorder and lack capacity to make this decision as long as minimum safeguards have been followed. The main purpose of the bill is to make those safeguards easier for professionals to manage and implement and therefore it makes it easier to deprive people of their liberty. The bill does not make it clear that deprivation of liberty cannot be used when other less restrictive options, such as providing more support in community, supporting a person in a different way, or looking at and addressing the true reasons behind a person's "challenging behaviour" could work to achieve the same aim. There is little in the bill to prevent deprivation of liberty being used as a way to deliver care in a way that is most convenient for professionals as opposed to the best option for the person concerned. Consultation and survey participants also expressed the following views and concerns about the Liberty Protection Safeguards, as set out in the bill:

Disabled Self-Advocates

Disabled people asserted forcefully that decisions regarding their liberty should remain with them, with the support of those they choose:

“It’s my choice. It’s up to me, not you.”

“It’s okay for my mum to help me make my own choice.”

“I feel my freedom is taken away when I am stuck without support not being able to do the things I enjoy. I don’t lose my freedom when support is there to help me do what I like doing, even if they stop me from doing something dangerous. Need to look at the bigger picture.”

Two people simply replied “no” to the question of whether care home managers or local authorities should assess whether a person should be deprived of their liberty. This is a powerful, categorical assertion refusing any professional involvement, that perhaps stems from a mistrust of professionals:

“How do we know if managers will give good support?”

Almost all participants at the consultation event shared stories of professionals making bad decisions for them:

“If my social worker got her way, I would be in a care home, miserable and feeling sorry for myself. I had to fight and now I live happily in my own flat with the person I love.”

There was strong concern about the risk of abuse and conflict of interest if either care home managers or local authorities were given the role of making decisions about the deprivation of liberty:

“There is a massive conflict of interest for both local authorities and care home managers to assess whether a person needs to have their liberty restricted, particularly when financial decisions influence choice of care placement, care plans, and care arrangements.”

The respondents felt that access to independent assessments by an approved mental capacity professional should be extended because the test of whether or not a person is objecting is not a reliable test.

“We are also not happy with this bill not including an independent assessment for everybody, as opposed to a small group of people who can access the complaints system.”

In such situations, many Disabled respondents advocated a group decision-making procedure when considering the deprivation of the liberty of an individual lacking mental capacity. Such a team approach should involve:

“the person concerned, family, supporters, psychologists, social workers, advocates”, and it should aim at equality and non-discrimination to

“maximise rather than restrict the cared-for person’s liberty, on the same level enjoyed by non-Disabled people.”

Non-Disabled Supporters

The responses of non-Disabled respondents were a little more equivocal, with only one participant presenting the form of a rights-based argument against the deprivation of liberty expressed by several Disabled participants:

“Allowing others to make this decision for individuals who lack capacity is a breach of their rights and allows for the misuse of this power.”

Other participants in this category seemed more comfortable with the deprivation of liberty of people lacking capacity. However, they also expressed a number of reservations. One such reservation concerned doubts about the abilities of those making decisions about the deprivation of liberty, and the need for relevant training:

“In my experience care homes have difficulty completing DoLS applications in the first place.”

[There is a] “Lack of MCA knowledge in care homes.”

“We also questioned if specific training would be given to care home managers and if consideration would be given to their professional background/level of experience”.

Likewise, there was a concern that the existing rights of people lacking capacity should not be eroded through this bill:

“We need to look at ways in which to support people’s needs rather than have their choices taken away.”

“I would not want [the MCA 2005] watered down.”

In terms of how decisions regarding the deprivation of liberty should be made, a number of points were made. There was distrust of care home managers and other professionals:

“NOT ... individual care home managers.”

“The manager is in *no way* independent”

“Not these professionals!”

The key message from Disabled self-advocates was that anybody who they trust and who takes time to get to know and understand them can make important decisions about their lives. Distrust in professionals was mainly explained by incidents of abuse, bad personal experience or the fact that they are fixed in certain ways of doing things and don’t take time to get to know or understand the person.

A range of potential decision-makers were suggested by non-Disabled supporters:

“local authority”

“judge”

“senior psychiatrist”

“managers”

“family members”

Several respondents advocated a team approach to decision-making regarding deprivation of liberty:

“This should be done on a joint basis.”

“A joint decision... multi-disciplinary team/ best interests.”

“A team effort involving the person, their family, and the local authority.”

One area in which there was a degree of disagreement among respondents in this category was concerning access to independent assessments and the role of complaints in making this determination.

Some people felt that it was not appropriate to rely on an individual's attempt to complain:

“Many people are not able to express their dissatisfaction due to mental disorders, even if they are unhappy with their care”.
“...not just if they complain”

However, in a departure from the views of Disabled respondents, several respondents believed it is appropriate to wait for the individual to complain before commissioning an independent assessment:

“When individuals are actively objecting... verbally, or trying to leave, challenging behaviour...”
“It's not necessary for all applications to require an independent assessment. In most cases it's not.”

It is possible that such reliance on complaints, or active objecting to deprivation of liberty could be to do with concern for resource implications, as suggested in this comment:

“...we know this can, and is proving to be an overload of demand on these services.”

Therefore, while there is clearly some overlap in the views of Disabled and non-Disabled respondents, it is certainly the case that while Disabled people are very concerned with the protection of the right to liberty, non-Disabled respondents are more likely to be swayed by resource constraints.

Key Points

Disabled people are very concerned about the possibility of being deprived of their liberty and the potential loss of decision-making authority in this regard. Some of the disabled self-advocates responding to the survey could foresee no circumstances in which they could countenance the deprivation of their liberty; a view that is perhaps the most closely aligned to the provisions set out in Article 14 UNCRPD, that no one should be deprived of their liberty due to their disability. For those who could foresee such circumstances, it is crucial that their views are represented through the decision-making process, by consultation with those who know them. The pursuit of equality should be

paramount, with the right to liberty of disabled people being viewed and protected in the same terms as that of people who are not Disabled.

This proposed reform of English and Welsh law concerning the deprivation of the liberty of adults who lack the capacity to consent to such deprivation represents an opportunity to bring the law into line with the international human rights treaty obligations and to positively acknowledge the Concluding Observations of the UN Committee in 2017.

Such an opportunity should be seized in order to achieve the positive progress of disability rights for people who are deemed to lack or may lack capacity to make decisions in England and Wales.

Recommendations

- **If there is a definition of deprivation of liberty it should better reflect the reality of life and feelings of individuals concerned.**
- **Deprivation of liberty can only happen when no other alternatives exist or could be put in place. Too often there are no alternatives because local authorities fail to commission sufficient effective support in community. There must be a duty to take proactive steps to put less restrictive alternatives in place.**
- **There needs to be easy access to independent assessments and effective ways to challenge decisions to deal with distrust in professionals that disabled self-advocates and families have.**

Concluding Remarks

The analysis above has revealed several key findings in terms of the views of Disabled self-advocates regarding issues arising in the Mental Capacity (Amendment) Bill. These can be summarized as follows:

- Disabled people unequivocally value the right to support to access decision-making autonomy.
- There is a strong emotional dimension to supported decision-making for Disabled people.
- Advocacy is key to the abilities of Disabled people to access their right to decision-making autonomy.

- Advocacy is about being heard and addressing the power imbalances between people lacking mental capacity and the institutions and services that support them.
- The right to participate in court proceedings and express views is a key aspect of Disabled people's struggles against unsatisfactory or oppressive care when they lack mental capacity and may be deprived of their liberty.
- Disabled people are extremely concerned about the protection of their right to liberty and advocate for this forcefully. If decisions are to be made regarding the deprivation of their liberty, they articulate a demand for those to be involved who know them well, and who they trust.

A further significant finding has been the degree of difference between the views of Disabled self-advocates and their non-Disabled supporters. This shows that it is vital that Disabled people and our organisations are continually consulted concerning the development of legislation and policy that has the potential to impact on our lives in a profound way.

References

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Appendix 1

Questions for survey of disabled self-advocates and non-disabled supporters

1. Should people be given the right by law to say who they want to support them to make decisions?
2. When should someone else be able to make a decision which is different to what the person wants?
3. Should care home managers or local authorities assess whether a person should be deprived of their liberty?
4. When should someone get an independent assessment from the local authority?
5. Should it be up to care homes to decide if a person gets an advocate?
6. Which people need an advocate?
7. What should advocates do when a person is complaining about their care?
8. When should people have the right to go to court and tell the judge what they think about their care?
9. Is there anything else you would like to say about these proposed changes to the Mental Capacity Act 2005?