

## Supported decision-making from theory to practice

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DOI:  
[10.3390/soc8020025](https://doi.org/10.3390/soc8020025)

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*Document Version*  
Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*  
Harding, R & Tascioglu, E 2018, 'Supported decision-making from theory to practice: implementing the right to enjoy legal capacity', *Societies*, vol. 8, no. 2, 25. <https://doi.org/10.3390/soc8020025>

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Article

# Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity

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Received: 29 March 2018; Accepted: 21 April 2018; Published: 24 April 2018



**Abstract:** The right to equal recognition before the law, protected by Article 12 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), mandates the use of supported decision-making practices to enable disabled people, particularly those with intellectual and/or psychosocial disabilities, to enjoy their legal capacity. Finding ways to translate this theoretical mandate into practice poses a number of particularly challenging socio-legal issues, which this research seeks to address. The English Mental Capacity Act 2005 (MCA) sets out a right to support with decision-making (s.1(3)), underpinned by a presumption of capacity (s.1(2)). Qualitative interviews with intellectually disabled people, their supporters, and care and support professionals were undertaken to explore how disabled people make decisions in their everyday lives, the kinds of support they need, and the strategies for supported decision-making used in practice. Analysis of these interviews suggests that a range of supported decision-making techniques have been developed in practice and are effective in supporting everyday preferences and some life choices. Paradoxically, it appears that as decisions become more complex, the support available to disabled people reduces. Specifically, much less support is available for more difficult decisions around finances, healthcare and legal matters. We argue that the reasons for this are due to a web of regulatory, social and policy issues. We conclude that implementing the right to enjoy legal capacity through supported decision-making will require a combination of regulatory reform, social change and policy amendment.

**Keywords:** legal capacity; mental capacity; supported decision-making; UN Convention on the Rights of Persons with Disabilities; care; human rights

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## 1. Introduction: The Right to Support with Legal Capacity

The right to equal recognition of all persons before the law is an important and long-standing legal principle. People with intellectual disabilities (we define as including those with learning disabilities, acquired brain injuries, and dementia) have often been denied their right to equal treatment before the law. We use the term ‘intellectual disability’ as this is the term used by the Committee on the Rights of Persons with Disabilities (CommitteeRPD), whilst being mindful of the different terms used across cultural and jurisdictional contexts. Throughout history, jurisdictions across the world have implemented systems which legally remove the rights of intellectually disabled people to make decisions about their own lives, on the basis of perceived limitations in their ‘mental’ capacity. These legal frameworks have had various names, including guardianship, wardship, lunacy administration and other terms, but the key commonality has been that people with disabilities are treated differently under the law than non-disabled people because of their impairments, and that another person makes substituted decisions for them, usually following appraisal of the disabled person’s ‘objective’ best interests [1].

In recent years, an international consensus has begun to emerge about the limits of approaches to legal capacity that remove all or some of the individual's decision-making rights [2]. This 'paradigm shift' in disability law [3] follows the ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and in particular the interpretation of the rights contained therein by the CommitteeRPD. The CommitteeRPD have argued forcefully for a move away from objective best interests, towards support to exercise legal capacity in all contexts, through supported decision-making wherever possible [4–7].

Much legal knowledge about mental capacity and decision-making in England and Wales is constructed through legal proceedings in the Court of Protection [8]. Disputed cases in the courts, however, make up a tiny proportion of the capacity assessments that happen and best interests decisions that are made in the lives of disabled people. The vast majority of mental capacity law happens in everyday encounters, between people with impairments that affect their mind or brain and those who provide services to them, support them, care for them or otherwise interact with them.

Using qualitative empirical research with intellectually disabled people and care and support professionals, the Everyday Decisions project sought to interrogate how everyday legally relevant decisions are currently made and supported, outside the confines of Court of Protection work. It explored how socio-legal understandings of 'legal capacity' (understood as the right to be recognised as a person in law, and to exercise legal agency [5,9]) and 'mental capacity' (understood as functional decision-making ability) interact in the everyday lives of people with intellectual disabilities, in order to generate new approaches to better support legal capacity in everyday legally relevant decision-making. In this paper, we outline key findings from the Everyday Decisions research about how supported decision-making happens in practice. This research shows that whilst the Mental Capacity Act 2005 (MCA) has proved to be a fertile regulatory landscape for supporting everyday choices and decisions about things like what to eat, wear or do, more complex decisions paradoxically receive less support. Life choices with further-reaching implications like decisions about housing, working and learning were sometimes appropriately supported, but sometimes insufficient support for these decisions led to difficulties around finding appropriate accommodation, navigating the welfare benefits and sanctions system, and finding paid work. Decisions that involve interactions with professional services like medical and healthcare choices, financial transactions and future planning through legal tools like wills, power of attorney or advance decision-making were often not as well supported as disabled people would like them to be.

We begin with an overview of the project methodology, before going on to set out how intellectually disabled participants and care and support professionals reported their experiences of supported decision-making across everyday preferences, life choices and more difficult decisional contexts. In the discussion section, we argue that the inverse relationship between level of support offered/experienced and the complexity of the decision to be made is a product of the regulatory system in England and Wales. We argue that the limited attention paid to supported decision-making in the MCA and its associated statutory Code of Practice has led to a lack of innovation in supported decision-making in social care practice. We argue that the CRPD provides a pressing mandate to revise the approach to supported decision-making in English capacity law and practice, and that doing so will require change across legal, societal and policy domains.

## 2. Methodology

The Everyday Decisions project involved qualitative interviews [10] with intellectually disabled people and social care professionals with experience of supporting disabled people. A total of 46 participants (15 disabled people, 6 supporters, and 25 social care professionals) took part in the study. Participants were drawn from various locations across England and Wales. All interviews were audio-recorded with the consent of participants. Video recording was additionally used for interviews with intellectually disabled participants to enable analysis of non-verbal communication where appropriate. This research engaged specifically with the rights and experiences of people with

intellectual disabilities. We understand intellectual disabilities to include a wide range of learning disabilities, learning difficulties, acquired brain injuries and other cognitive impairments however caused, including degenerative neurological conditions like dementia.

All participants had capacity to consent to participation in the research, and consent processes were carefully constructed and carried out in a way that ensured participants had the chance to ask questions, clarify issues and provide informed consent. All names used are pseudonyms, and any information that could identify individual participants has been removed to protect the confidentiality and anonymity of participants. As participation in the project was restricted to those who would have the capacity to consent, approval from a National Research Ethics Committee was not required for this project. Ethical approval was granted by the University of Birmingham Research Ethics Committee (ERN\_16-0736) before the empirical components of this project began. Disabled participants were recruited mainly through gatekeeper organisations, supplemented by direct advertising on the project website and Twitter account. Care professionals were recruited through the website, Twitter, and informal snowball sampling.

Intellectually disabled participants participated in interviews about their lives. Interviewees had a wide range of disabilities and impairments. Additional information about individual impairments is not provided to protect the confidentiality of participants. Interviews with disabled participants began with open questions about themselves and their lives, their likes and dislikes, activities and interests, before progressing on to questions around life choices and opportunities (housing, education, employment) and financial, medical and legal contexts. Interviews were structured as conversations between the interviewer (RH) and the interviewees, with support provided by a supporter of the interviewee's choice where necessary. All disabled participants had some verbal communication skills, though many participants were helped in their expression and communication in the interviews by their supporters. A supporter was involved in 80% ( $n = 12$ ) of the interviews, with some supporters supporting multiple interviews. Of the six supporters, two were family members, two were personal assistants, one was a volunteer and one was a paid care worker.

Fifteen intellectually disabled participants took part in the project, around half ( $n = 8$ ) of whom also had physical disabilities of varying degrees. Participants varied in age from under 25 to over 70 years old. Most participants were women ( $n = 9$ , 60%). All disabled participants and supporters were white British. Participants lived in a range of different housing contexts: five participants lived independently, six in supported living environments with varying degrees of independence, three with their families, and one in a residential care home. Demographic details for disabled participants and supporters is available in Table 1.

**Table 1.** Demographics: Disabled participants.

Age Group		Gender	
18–24	6.6% ( $n = 1$ )	Male	40% ( $n = 6$ )
25–34	20% ( $n = 3$ )	Female	60% ( $n = 9$ )
35–44	13.3% ( $n = 2$ )	Disability <sup>1</sup>	
45–54	26.6% ( $n = 4$ )	Learning difficulty	80% ( $n = 12$ )
55–64	26.6% ( $n = 4$ )	Sensory impairment	13.3% ( $n = 2$ )
65–74	6.6% ( $n = 1$ )	Physical impairment	60% ( $n = 9$ )
Relationship Status		Acquired Brain Injury (ABI)	13.3% ( $n = 2$ )
Single	33.3% ( $n = 5$ )	Autism Spectrum Disorder (ASD)	13.3% ( $n = 2$ )
Casual Relationship	26.6% ( $n = 4$ )	Supported at Interview	
Engaged	26.6% ( $n = 4$ )	Supporter present	80% ( $n = 12$ )
Divorced	13.3% ( $n = 2$ )	No Supporter	20% ( $n = 3$ )

<sup>1</sup> Totals here do not add to 100% due to multiple impairments.

Social care professional interviews used an in-depth, semi-structured approach. Of the 25 social care professionals who took part in the research, 8 participants (32%) worked in brain injury case management and 14 (56%) at various levels at care homes and day centres, including managers ( $n = 4$ ), support workers ( $n = 8$ ) and housekeeping staff ( $n = 2$ ). Two participants (8%) worked as mental capacity assessors and one (4%) as a best interest assessor. Only one participant was retired, with the rest working full-time ( $n = 24$ , 96%). Most care professional participants were women ( $n = 22$ , 88%) and identified as White English/Welsh/Scottish/Northern Irish/British ( $n = 20$ , 80%). Their income levels varied between £10,001 and £14,999 to over £50,000. Demographic data for social care professional participants is provided in Table 2.

**Table 2.** Demographics: Social Care Professionals.

Age		Gender	
18–24	16% ( $n = 4$ )	Male	12% ( $n = 3$ )
25–34	4% ( $n = 1$ )	Female	88% ( $n = 22$ )
35–44	24% ( $n = 6$ )	Race/ethnicity	
45–54	32% ( $n = 8$ )	Black African	4% ( $n = 1$ )
55–64	16% ( $n = 4$ )	Black Caribbean	4% ( $n = 1$ )
65–74	8% ( $n = 2$ )	Mixed (White/Black Caribbean)	12% ( $n = 3$ )
Highest Qualification		White British	80% ( $n = 20$ )
Unknown	8% ( $n = 2$ )	Occupation	
NVQ <sup>1</sup> Level 2	4% ( $n = 1$ )	Housekeeping	8% ( $n = 2$ )
NVQ Level 3	24% ( $n = 6$ )	Frontline Care Worker	20% ( $n = 5$ )
NVQ Level 4	4% ( $n = 1$ )	Team Leader/Coordinator	12% ( $n = 3$ )
NVQ Level 5	12% ( $n = 3$ )	Care Manager/Deputy Manager	16% ( $n = 4$ )
Professional qualifications	4% ( $n = 1$ )	Brain Injury Case Manager	32% ( $n = 8$ )
Bachelor's Degree	16% ( $n = 4$ )	Mental Capacity Assessor	8% ( $n = 2$ )
Higher Degree	32% ( $n = 8$ )	Best Interests Assessor	4% ( $n = 1$ )

<sup>1</sup> National Vocational Qualification.

Thematic analysis [11] of the qualitative research data was carried out by the research team, independently coding to an agreed list of deductive codes generated from the project research questions.

### 3. Results: Supporting Decision-Making in Everyday Life

Analysis of these interviews with disabled participants and care professionals found that decisions can be broadly classified into three 'types': everyday preferences, life choices, and difficult decisions. Everyday preferences include the kinds of choices that most people make on a day-to-day basis, about what to wear, what to eat, what to do or where to go that day. We describe decisions about working, learning, housing and relationships as 'life choices' and legal, financial and medical decisions as 'difficult decisions'. We address each of these decisional contexts in turn.

#### 3.1. Supporting Everyday Preferences

Participants in this research described high levels of nuanced support for everyday decision-making. Disabled participants reported being able to make day-to-day choices in their lives, and having these choices and preferences respected and facilitated by those around them. Many of our disabled participants pursued activities and interests in the community, which appeared vital in providing and realising the chance to live a fulfilling life.

I do college Monday and a Wednesday. I'm independent. I do enterprise activity, ... quizzes and that, sort of like that. Computers, IT suite like, yeah I do all that as well. [I go to the day

centre] on Tuesday, Thursday and Friday so yeah. So I go voluntary work on a weekend [in a charity shop]. Like polishing the rails and the shelves, and sometimes I do hoovering as well.  
(Winnie)

All of the intellectually disabled participants spoke of their choices and preferences around food, leisure and activities. Many of these participants had very busy lives—sometimes with different leisure activities, voluntary work or educational activities on every day of the week.

Firstly, what I do on the Monday, actually I do work in [a café]. And on Tuesday, me and my fiancée, we've been to [disability drama group]. And also me and Amanda, we do dance lessons. And also we've been to the social club. We do loads of activities there in the social club. We did karaoke. On a Wednesday is my day off. I do always go into swimming as my exercise. And also, oh yeah, we did keyboard lessons. And on a Thursday, I've been to the film academy. And me, tomorrow [Friday], I've got a [musical theatre] rehearsal.

(James)

These community activities not only allow people with intellectual disabilities to lead rich and fulfilling lives, they also allow the formation of peer networks, friendships and relationships. Self-advocacy groups were an important community activity for many of these disabled participants. Self-advocacy disability groups (e.g., People First organizations) provide important opportunities for disabled people to gain skills, generate training and employment opportunities, campaign for disability rights, and help support disabled people to speak up for themselves. Such organizations, which are run by and for intellectually disabled people appear key to effective supported decision-making in law and society.

Care professionals provided many examples of strategies to enable choice by people with intellectual disabilities on all aspects of everyday preferences, from food and clothing choices, to daily activities and holiday locations. All of these choices were underpinned by a focus on communication as the key to unlocking agency. Three key approaches to supporting everyday preferences reported by care and support professionals were:

- **Limiting options** by asking closed questions with few options instead of open questions.
- **Providing context** through jointly generating pros and cons about the decision at hand.
- **Establishing structures** to help individuals execute their decisions in a way that also provides room for flexibility.

Supporters use a wide range of communicative tools: verbal, visual and non-verbal, and they use those tools in a variety of ways. Some people may be supported to make a decision through being directly asked which of three or four options they would like to have, or instead, some may be able to do so through visual aids, through seeing the pictures of their options and expressing their decision by pointing to their choice.

To demonstrate the intricacies and complexities that supporting everyday preferences involves, we provide three examples of how care professionals have tailored their support approach to the individual's communication and decision-making style:

If we say to him "do you want to?" he will always say "no", automatically. So we don't use the phrase "do you want to," we say "come on, we're going to . . . ". If he doesn't want to do it, he will still say no, but he's more inclined to participate in stuff if you say "come on, let's do . . . ", or "we're going to do something". As I say, we're not taking his choice away, because he still has that choice to say I really don't want to, and he will do. But, as I say, given a direct choice "do you want?", "do you want a drink?" "No." "Do you want something to eat?" "No." "Do you want to go out?" "No." Everything's no. But that took us quite a while to figure that one out.

(Julia, Residential Care Manager)

What Julia describes here as the need to ‘word things differently’ was voiced by many other social care professionals as the need to formulate questions differently, to allow the person to take control of the interaction, and to seek other methods of interaction to provide support to the individual in line with their communication style as well as their decision-making approach. Less nuanced understandings of decision-making may take those negative responses at face value, with the consequence that the service user has no real opportunities to engage in activities.

Adrian shared examples of how the process of decision-making reaches beyond verbal communication. Adrian’s account on the support given to a disabled person to have a shower who found it difficult to translate his expressed wishes to shower with the action of doing so, shows how supported decision-making can sometimes take the form of the careful reorganization of space, objects and bodies:

So what we learned to do is you never say to him “is it time for your shower?”, because he’ll say “no, I’ll do it later”, because he had time perception problems. You never confront him by saying “you have to have a shower”, because that causes an argument and he’s ready for an argument at all times. [ . . . ] we got to the situation where the staff were, they were positioning themselves near the bathroom and as he walked passed they would say “would you like green shower gel or blue shower gel?” And he would say “blue”, and he’d go and have a shower. So we’d environmentally constructed for him to take a decision that was not only in his interest but was actually meeting his goals. He couldn’t do that without it.

(Adrian, Brain Injury Case Manager)

Finally, Leslie’s account demonstrates how a disabled person with no verbal or pictorial communication can be supported to express choice on where to go on holiday through multisensory means:

So we’re going to [the South Coast] because he loves the beach, and he also loves walking. He loves scenery. So, he’s got absolutely no verbal communication at all and yet he will go and stand on the edge of a waterfall or a mountain and just sit down and just stare out at the beauty of it. And it’s almost like he can’t communicate what he’s thinking about it but you can tell he really appreciates the beauty of wherever he is, because he will literally just sit there and stare in awe at whatever. So, he loves going places where it’s naturally beautiful and walking. But again, that’s more based on understanding of him, because [ . . . ] If you showed him five different pictures and talked it through, he wouldn’t actually have an ability to choose any one of those. So where we go with him is based more on our knowledge of what he enjoys. [ . . . ] people choose in different ways but people are given the information and a variety of information and then they choose wherever they want to go.

(Leslie, Care Manager)

Overall, these examples show that care professionals engage in a variety of strategies in order to communicate and convey support, and that decision-making processes cannot be limited to direct verbal communication or verbal output. Individualized verbal interactions as well as non-verbal cues, facial expressions, gestures, affect, senses, body movements, bodily dispositions, spaces and objects can play a significant role in facilitating supported decision-making. Experimentation is also an important element in developing communication strategies to support decision-making. Such experimentation often relies on years of experience, extensive periods of working with the individual, and a great deal of trial and error with different support mechanisms and structures. Supported decision-making is founded on a contextual understanding of the individual, their characteristics and relationships, as well as on a well-established, consistent and trusting relationship between the supported person and their supporter. These strategies also raise interesting questions about the appropriate balance between supported decision-making and substituted decision-making on the basis of the person’s will and preferences, an issue we discuss further in Section 4, below.

### 3.2. Support to Make Life Choices

As decisions became more complex, the relationship between the support our disabled participants reported needing and the support they received from care professionals became more complicated. For life choices, in which we include decisions about education, employment, housing and relationships, appropriate levels of support were not always available. We do not explore the issue of supporting relationships in this paper, as we have done so elsewhere [12,13].

#### 3.2.1. Education and Employment

Few of the care professionals we spoke to engaged with issues of education or employment. In contrast, most of the disabled participants told us about their experiences of working and learning. Several disabled participants told of attending college, with mixed levels of success. Where educational opportunities aligned well with their preferences and interests, opportunities for further education were very positive. James, for example, studied arts, fashion and music technology at college, which he found to be a very rewarding experience. Where educational opportunities were not well aligned with their wishes and preferences, these disabled participants reported less positive experiences. Amanda did not have as much choice about what to study at her local college, and so gave up going to college. She now undertakes a training for work placement which is better suited to her skills and interests. Other participants gave rather troublesome accounts of leaving education or employment:

I did go to college. [ . . . ] And there was a bit of bother, bullying sort of thing. I can cope with bullies but this was just a bit too far. And I chose, I didn't like the course anyway, it was gardening and gardening wasn't for me. I don't mind pottering about here doing the weeds outside, but this was full-on building and brickwork.

(Alex)

Alex gave two reasons for giving up his college course: he mentioned that the subject of the course, which involved garden landscaping, wasn't right for him. Unfortunately, he also referred to "bullying" as a reason for giving up on his college course. This suggests that not only would better support for educational choices which align well with disabled peoples' interests and preferences be beneficial, but also better support when problems occur within educational contexts would allow people with disabilities to continue in education longer, providing greater future employment opportunities.

Most of these intellectually disabled participants reported undertaking some voluntary work, often in charity shops, and often doing manual labour like cleaning, but also in community voluntary services like disability sport, community keep safe schemes, visiting older people, and volunteering in self-advocacy organisations. All of those participants who spoke of either past or current experience working in a voluntary capacity would like more employment opportunities and would like to engage in paid work. Three of the younger participants (aged 25–34) reported engaging in paid work, which they enjoyed: James worked one day per week in a café; Amanda worked a day a week in a hairdressing salon; and Carrie had previously worked a few hours a week in a clothes shop, but had recently been made redundant, and is now actively looking for new opportunities for work.

I've looked for a few jobs. I've looked for schools and making teas and probably working with old people but [ . . . ] there's an old people's house. They've sent, mum sent a CV in and they haven't got anything going at the moment but hopefully when something comes through then there'll probably be a job.

(Carrie)

Some older participants spoke of previous work in manufacturing or specialist disability employment roles. Rebecca, for example, previously worked in an adult training centre, making cord stools and cane trays, which she said she enjoyed. She now does a lot of volunteer work, and has recently been trained by a mentor to use the till in the charity shop she works in. Similarly, Tracey



spoke with pride about her previous work in a shoe factory, but “that was 2004 when I got made redundant and since then I’ve only done like charity shops, but now, because I’m worse disabled [physically] I can’t do a lot, but I am doing an English course”. In summary, there appear to be quite limited employment and education opportunities for intellectually disabled people. Yet all of these participants enjoyed the work that they either currently do or have done in the past, and would value opportunities to engage in suitable paid employment. The question of paid employment is, of course, linked to the issue of benefits and sanctions. Two of these participants spoke directly about problems with benefits relating to employment, other participants highlighted the impact of the so-called ‘bedroom tax’ on their housing choices.

During a discussion about benefits, Beth (a supporter), told an all-too-familiar story about the challenges of keeping track of benefits in the age of sanctions:

They both should get ESA in the Support Group, however, James’s hasn’t been paid [for five months] because allegedly they sent a letter to where he used to live saying he had to go for an interview—which he shouldn’t have to go for an interview [because he is in the support group], but they wrote saying he had to go for an interview—and no one seems to know anything about this letter. And they never send a follow-up or a request: could you get in touch because you didn’t go to your interview. And so his payments were just stopped. Because James’s mum couldn’t understand why James didn’t seem to have any money and yet Amanda, since she’s moved in here, is paying out for more things, has no less money than she had before. And so that’s obviously being chased up at the minute.

(Beth, Supporter)

Here, we see some of the challenges that people with intellectual disabilities can experience when confronted with official correspondence. It seems that this particular letter was sent in error, and the sanction was also applied in error, as James is entitled to ESA in the Support Group. Yet as a result of this error, James has been without his major income replacement benefit for five months, at a time when he had just moved in with his fiancé and had higher-than-average expenditure needs. James’ parents are working to resolve this issue on his behalf, but errors of this nature simply should not happen.

Another participant, Suzanne, explained that she had been accused of falsely claiming benefits because she had travelled to different organizations four times in a year to promote disability sport and had not secured permission to work. Suzanne’s story highlights the ways that physical health problems can compound the difficulties of navigating the social welfare system for people with intellectual disabilities.

In 2015 when I got cancer, I worked four times in that year going to organizations and saying this is what [disability sport] is like, and so I basically I’ve just expenses and I got £115 for doing it. But that happened four times that year and. And social security have got onto me and said “right you owe us £1000 for falsely claiming benefits”. And I said look, I know, I know, I said look I’ve got permission to work in 2016, and the reason why I didn’t get permission to work in 2015 is because it was just like too much for me to think about. I had enough thinking about like staying alive, let alone like I don’t know, I don’t know. [ . . . ] So yeah, I said, you know, it was just too complicated to jump through all the hoops when I couldn’t even really think what I was on about half the time. You know, because you do get, chemo, you know, your brain it kind of goes absolutely to pieces when you’re on chemotherapy. I was just, it was pretty awful. You know, I wasn’t in the mood to like go press one if you think this, press four if you think—I just couldn’t concentrate on anything. So I’ve not heard from them yet to whether I’ve got to pay, that was my appeal.

(Suzanne)

These experiences highlight a major tension between intellectually disabled people's desires to lead meaningful lives, to work and to contribute to society, and the bureaucratic, punitive, sanctions-focused nature of the contemporary UK state benefits system.

### 3.2.2. Housing and Accommodation

The findings from this project told a mixed tale around housing and accommodation choices. Whereas many of the disabled participants were happy with their accommodation, others were living in unsuitable provision, had struggled to find appropriate accommodation, or had waited a long time in unsuitable accommodation before finding an appropriate home. As may be expected, decisions around housing require the balancing of a range of competing demands around location, size, available accommodation, appropriate care and funding constraints. Care professionals who had been working in the sector since before the Mental Capacity Act 2005 came into force reported an improvement in the approach to placement decisions:

They were able to ask questions about where it was, who they'd be living with, what the environment was like, and also have pictures, given the option if they'd like to come out for a visit, if they'd like to come for tea, if they'd like to come and have an overnight stay. So if they said I don't like it—because we had a vacancy for a little while because we had a chap who moved out into supported living, and somebody did come and they went "I don't want to live here," so they didn't move in. People actually were given that choice and I think it's slightly different now, whether people are given a greater level of input on where they want to live. When this was opened in 2005, and all the assessment work took place in 2004, there was no choice given by the local authority; they were just told this is where you're moving to. But obviously we do things differently now.

(Leslie, Care Manager)

This story directly contrasts the pre- and post-2005 approach, which demonstrates some forward movement in supporting housing decisions for disabled people.

Two key issues that were raised by disabled participants in relation to housing were the length of time it can take to find an appropriate home, and the impact of 'bedroom tax' on their accommodation choices. Michelle, for example, moved into her own place six weeks before the interview, having previously lived in a group house, and a residential college before that, "I wanted to do that for about, it took me about two and a half years. I was on the key wait for ages. Because they couldn't find anywhere suitable." Tracey was also looking for a new house because of a deterioration in her mobility:

I'm on house swap and I'd like to move down town a bit nearer or somewhere that ain't far from the shops. Make it easier for me because when I go home now I've got to go down to the town, catch the bus, come back and then I've got about five minutes' walk, but it takes me half an hour. So I'd like to be a bit nearer the town. But I like the place where I am. It's a one-bedroom flat and it's big enough for me so that's what I'd like to do. If I had a two bedroom, it'd be ideal but you've got to pay bedroom tax. You see, my boyfriend, he's got a two-bedroom bungalow but he's got a lodger. You see I would like a bungalow, a one-bedroom bungalow, but there's not many around. So I'm stuck really where I am.

(Tracey)

The contemporary limitations posed on housing choices for individuals reliant on state support (the 'bedroom tax' and the shift to Universal Credit) are also compounded for people with intellectual disabilities. Finding a suitable property through housing swap is difficult enough, even without the added challenges posed by balancing physical needs and intellectual disability. Whilst housing decisions are inevitably constrained by available properties and support, the participants in this study appeared particularly constrained in the choices available to them around housing.

### 3.3. The Challenges of Supporting Difficult Decisions

Participants in this research reported limited availability of support for more complex decisions, by which we mean decisions which may require the decision-maker to understand and process greater quantities of, or more difficult, information, or wider and/or more abstract potential effects. These include decisions about managing finances and investments, medical decisions and legal decisions like wills, power of attorney and advance decisions to refuse treatment or end-of-life planning. The amount of support available to disabled people from frontline care professionals appeared to reduce in an inverse relationship to the complexities of the decision they needed to make. So, for example, whereas day-to-day financial matters were relatively well supported, there was very little engagement with more complex financial decisions, which were instead passed on to more senior levels within an organizational setting.

I think it's part of our company policy that we become corporate appointees for benefits and so on and so forth. But there are quite a few of our service users that are under the Court of Protection. So everything goes via them anyway. That tends to be done at the main offices, we don't have a lot to do with, I just ring up and go "have they got," "we need." So we order the money once a week for their activities, for their toiletries and anything else they need and I just go and fetch it on a Thursday [ . . . ] We have a finance department, so I don't deal with any of that. I get involved in filling forms in for benefit offices, and that's probably my limit to be fair. I leave that to the experts, because I don't really know. So if we did have any issues, I would speak to my financial, [ . . . ], our financial director and pass anything [on]. The same as the wills and stuff, I would seek advice from him, because he knows more than I do.

(Julia, Care Manager)

Here, we see that whereas day-to-day finances are managed by frontline staff (by which we mean those who have contact with service users on a regular basis, whether in a hands-on or managerial role), any more complex matters are passed up to centralized or more distant decision-makers. A similar approach was often described for medical and legal issues:

With medical treatment, that will be more towards senior/management/deputy side, not so much my role. Like if I was to be concerned about something like oh so-and-so's looks a bit poorly today or is showing that he might have a headache or a tummy ache, then I would then go to my senior and be like "this service user will need to be monitored throughout the day." So that's what we will pass on: just our concern.

(Nancy, Care Worker)

Yes, I think power of attorney, a lot of that would go directly to the manager and she will make the arrangements for that. We wouldn't at this level be getting involved in that. Yeah, she would be getting involved with that, and it would be her and operational manager, the individual's family and a best interest meeting would be called for that really.

(Nicole, Senior Care Worker)

This finding, that frontline care staff do not generally feel able to support more complex decisions, is unsurprising, as it highlights that a level of expertise is needed to support and advise in these areas. In many cases, care professionals would turn to independent advocacy services to get support for service users who needed assistance in making more complex decisions. Yet, as Alice (Case Manager/Occupational Therapist) said, highlighting the pressure on advocacy services: "I know you're meant to have [Independent Mental Capacity Advocates] IMCAs, but trying to get an IMCA is a nightmare." Instead, therefore, these more complex decisions get passed up through

institutional hierarchies, away from the person at the centre of the decision, and into substituted decision-making frameworks.

In contrast, the disabled participants we interviewed for this project highlighted that legal, financial, and medical decision-making was more difficult for them, but rather than wanting someone else to make those decisions, they sought additional support with making them. A common strategy was to take a supporter to medical appointments to help them understand:

If I have to go to the doctor, I mean I think we know what GPs are like, how they present information and how difficult it is. And I understand, I don't always quite understand even though I think I understand. And I'll make an appointment now and I'll say to [my PA] "OK I've got this appointment later on today, . . . will you come with me?" Because I need to make sure I get the right information, understand what I'm taking and how much I'm taking.

(Gareth)

Two disabled participants, Carrie and Alex, described having given members of their family Lasting Power of Attorney to help them in medical and financial situations.

For instance she's done, my mum's done the health one because when I go to the doctors I clam up, I struggle to explain myself, especially, and mum always talks to me. I go in there and I don't, I clam up or. Because of my anxiety, when I'm in a real high state of anxiety, because I suffer from anxiety, I am sweating. I can't talk, I'm shaking. It's like I want to break out the building. And especially in them sorts of places. . . . They're very difficult as it is, but the dentists know me, and that's a good thing. But I just want to just have her there. Because say like if I, god forbid I was rushed into hospital for anything, she knows what I want. If I can't speak, I can speak up for myself, that's the problem, I can. But in certain respects I can't when it comes to my health.

(Alex)

We found very little evidence of supported decision-making in respect of broader legal matters in this research. Rather, frontline care staff were not themselves confident about managing their own legal choices. As Julia (Care Manager) put it: "I wouldn't know how to make a will. No chance. As I say, I need to do one myself." We cannot, therefore, expect individuals who have limited understanding of legal issues to support others to make decisions about them. This suggests that there may be a previously unidentified skills gap and training need within the care workforce.

### 3.4. Summary

In summary, we found that some excellent strategies had been developed and were used in daily care practice to support disabled people to express their everyday preferences. Many disabled people were well supported to make at least some important life choices, especially those around education and employment. Other life choices, which relied more heavily on external support or provision, or which balanced multiple factors of availability and cost, were often less well supported. More complex decisions, around financial, legal and medical matters, were often addressed through substituted decision-making under 'best interests' or sometimes by nominated supporters through Lasting Power of Attorney frameworks.

## 4. Discussion

The findings from this research reflect contemporary concerns in mental capacity law and disability studies scholarship about the right to equal treatment under the law. It is clear from these findings that whilst the MCA is a helpful legal framework for supporting everyday preferences, it has not yet been able to catalyse a shift to supported decision-making in relation to wider life choices or complex decisions. This can be explained by exploring the social, legal and policy conditions that underpin contemporary practice.

#### *4.1. Social Context: Disabled People's Decision-Making Rights*

A key reason why the right to equal treatment under the law, as protected by Article 12 CRPD, has been so controversial [2,14,15], is that normative disagreement remains across domestic and international contexts about the extent to which people with intellectual disabilities should be entitled to make their own choices about their lives. Even leaving aside the disputes on the wording of the convention outlined by Dhanda [2], the findings from this project demonstrate that frontline care professionals, many of whom have had significant training in the domestic legal context of the MCA, still default towards best interests, rather than taking the presumption of capacity seriously. Significant work therefore remains to be done in making the case for why all disabled people have the right to make their own decisions, or to have their wishes and preferences forming the core of any decisions made on their behalf.

It is becoming clear from international scholarship, and from legislative changes in other jurisdictions, that supported decision-making under the CRPD requires something more substantive than the version set out in the MCA [16–22]. At present, the chapter on supporting decision-making in the MCA Code of Practice [23] (pp. 29–39) focuses almost entirely on communication, rather than on broader decision-making supports. Whilst communication is extremely important, especially for everyday preferences, the findings from this research demonstrate that supported decision-making, if it is to support the legal capacity of those who have impairments that affect their decision-making abilities, needs to be both broader and deeper than the current MCA Code of Practice suggests. If we agree that supported decision-making is a necessary element of the implementation of the right to equal treatment under the law (which those jurisdictions that have ratified the CRPD should do given the lack of ambiguity of the CommitteeRPD's position in their first general comment [4,5]) then much more emphasis needs to be placed on the mechanisms through which intellectually disabled people can exercise their legal capacity.

Addressing this broader context of supported decision-making will require some additional training for frontline care professionals, in supporting a wide-range of decisions, in making complex information accessible, and in the underlying rationale for the right to enjoy legal capacity on an equal basis with others. If this responsibility to increase the skill level of the care workforce is taken forward, there would likely be some attendant benefits for the sector through a re-valuation of the role of care in society [24]. Addressing the social context of care and supported decision-making is, however, only part of the challenge. There are two further matters that interlink with this social context that also need to be resolved. These are: the relationship, and fine balance, between supported and substitute decision-making and how legal frameworks can respond to this; and the need for policy changes which recognize that legal capacity requires support across multiple domains.

#### *4.2. Legal Context: Walking the Tightrope Between Supported and Substituted Decision-Making*

In the findings set out above, and in other publications from this study [13] we have reported stories of supporting decision-making told by care professionals that seem to suggest that supported decision-making can involve elements of persuasion, or even manipulation. Consider, for example, the story told by Adrian about supporting a client with an acquired brain injury to maintain personal hygiene (reproduced in Section 3.2, above). Here, we see physical space, and the person's communication difficulties, being manipulated in the service of supporting him to choose to take a shower. Similarly, in Leslie's story of choosing to take a non-verbal service user, whom she reports as unable to make an express choice, on a walking holiday near the coast, we see a decision that looks more like a substituted decision than a supported decision. Supporting legal capacity in this way raises questions about the appropriate balance of supported and substituted decisions, and the appropriate legal response in these situations.

We consider that it makes sense to understand decision-making on a continuum, from fully independent decisions at one end through to fully substituted decisions at the other end. Decisions at the fully independent end might be those of the autonomous man of liberal theory [25]. Examples of

decisions at the fully substituted end might be the objective best interests decisions of the pre-MCA inherent jurisdiction (e.g., *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1). Decisions taken under the MCA reach neither of these extremes. If, as we would argue, everyone makes decisions in, by and through their relational contexts [26], then the fully autonomous end is but a fiction, which ignores the reality of decision-making support that we all draw upon. Similarly, if, as Lady Hale convincingly set out in *Aintree University Hospitals NHS Foundation Trust v. James* (2013) UKSC 67, ‘the purpose of the best interests test is to consider matters from the patient’s point of view’ (at paragraph 45), the fully substituted, objective best interests model no longer has a place in English law. Instead, all decisions along the useable extent of our decision-making continuum require some form of support. If we understand all decisions (irrespective of disability) as involving some support, the question then becomes about where law should intervene to create safeguards against abuse, or undue influence, rather than targeting interventions at particular groups that are assumed to require support.

Thinking back to our two examples, we would argue that these specific examples are entirely compatible with the individual’s rights under Article 12, as expressed by the CommitteeRPD. It matters little whether an individual communicates through verbal expression, or through bodily and emotional expression. It is clear from Leslie’s story that the service user’s wishes and preferences have been at the heart of the choices made about holiday location and activities. If we look at the text of General Comment 1 [5] (as amended by the 2018 corrigendum [27]), we see that substitute decision-making regimes are defined as:

Systems where: (a) legal capacity is removed from a person, even if this is in respect of a single decision; (b) a substitute decision maker can be appointed by someone other than the person concerned; or (c) any decision made by a substitute decision maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.

The MCA as a whole is, undoubtedly, a system which involves substituted decision-making. The functional test is used to deny legal capacity on the basis of impairments in mental capacity, and there exists a framework both for the formal appointment of deputies, and for informal decision-making by other parties. These examples of supported decisions, to go on holiday, or to take a shower, do not, however, include the formal substituted decision-making elements of the MCA. Instead, they can be understood as examples of supported decision-making, following the presumption of capacity. The care professionals involved have presumed capacity to choose to wash, and to go on holiday. They have considered the individual communicative style of the person they support, and they have considered that person’s verbally and interactionally expressed wishes and preferences in order to help them to make a choice to undertake the activity in question. Certainly, these decisions are closer to the substituted, rather than independent, end of the decisional continuum, but the clear focus on facilitating the person’s will and preferences means that they fit well with Article 12 CRPD. This is not, however, to suggest that manipulation or persuasion would always be appropriate. Where, for example, ‘support’ gives way to deception or coercion, it would not follow the spirit or letter of the CRPD.

There are, of course, further questions to be addressed around the issue of regulating supported decision-making. Some scholars have made significant inroads into thinking through what a CRPD-compliant regulatory approach to supported decision-making might look like, and the theoretical underpinnings of this new paradigm of legal capacity [4,6,9,19,22,28–31]. There is not the space in this article to do justice to these questions. Instead, we consider it important to simply note that the CommitteeRPD were also clear in setting out that “systems of supported decision-making should not over-regulate the lives of persons with disabilities” [5] (p. 7). Any response, therefore, to the challenge of constructing a supported decision-making framework must bear this in mind, whilst also ensuring that it creates the conditions possible to support decision-making across everyday preferences, life choices and the more complex and abstract decisions that arise in financial, medical and legal contexts.

#### 4.3. Policy Context: Supporting Legal Capacity Requires Support across Multiple Domains

The final issue that we wish to discuss in this article is a policy question relating to the scope of supported decision-making. The MCA considers functional capacity on a decision-specific basis [23]. This decision-specific approach is designed to recognize the differential cognitive processes involved in, for example, deciding what to eat for lunch and deciding whether to write an Advance Decision to Refuse Treatment. This regulatory approach goes some way to explaining the differential treatment we have found in this research relating to everyday preferences, life choices and difficult decisions. Our research shows that the MCA has facilitated a culture of supported decision-making for everyday preferences. In some cases, disabled people are also provided with the support they need from their family, paid carers and professionals to make choices about significant areas of their lives. Yet when more complex issues arise, these are presumed too difficult to simplify into alternative communication formats. As a result, people with cognitive impairments are not supported to make their own decisions in these areas. The question of supported decision-making then collapses into best interests substituted decision-making, as provided for by s. 4 MCA, and the associated chapters of the Code of Practice [23].

In 2017, the Law Commission recommended some changes to the best interests framework in the MCA to foreground the person's wishes and preferences, which may well go some way towards bringing the MCA closer to CRPD compliance [32]. Yet our empirical research suggests that bringing English law and practice into line with the CRPD will require more than technical legal changes. We consider that any system built from an approach that relies on functional capacity assessment might run the risk of replicating the inversion of support available vs. decisional complexity that this research uncovered in contemporary practice under the MCA. Instead, we consider that the imperative to avoid over-regulation in disabled people's lives through a supported decision-making framework [5] means that we need to think of the issue of supporting legal capacity in a much more holistic sense.

The contemporary regulatory framework, as enacted by the MCA, begins from the perspective that there are some people who cannot make decisions for themselves, and that a legal framework is required to authorize others to make decisions as necessary, and to protect those individuals from abuse, neglect or other harm [33]. Notwithstanding the potentially empowering nature of the MCA, this research suggests that the MCA's decision-specific approach, underpinned by the functional assessment of capacity allows and indeed facilitates the drive towards substitute decision-making for more complex matters. By focusing on communication as *the* means towards supported decision-making [23], and by constructing capacity assessments as complex appraisals of a person's abilities, as has become normative within Court of Protection practice [34], the regulatory framework created by the MCA disempowers care professionals from putting in place wider and more holistic support frameworks. The decision-specific approach of the MCA also isolates decisions from their larger contexts and overshadows the long-term needs of both care professionals and disabled people to co-develop support structures and practice decision-making skills over time across multiple life domains.

We consider that the policy conversations that would underpin any future changes to the MCA approach to bring it into line with the CRPD therefore need to avoid beginning with questions of protection, or of who is legally entitled to make a substitute decision. Instead, they should start by asking what support people who have a range of intellectual and psychosocial disabilities might require to live fulfilling, ordinary lives. Starting from the perspective that everyone has the right to enjoy their legal capacity enables a policy conversation that prioritizes rights to support across a wide range of life domains. Life choices and complex decisions are interconnected; choices that we make about, for example, working and learning have implications for financial matters, including welfare benefits and 'sanctions'. Supporting people to make decisions about employment or education therefore also requires that we support them to navigate the system of benefit and support entitlements. Other decisions are similarly interconnected: everyday food preferences have implications for bodily health; choices about care provision and location have profound effects on housing, privacy, family life. Recognizing this interconnected nature of decision-making, rather than the decision-specific approach

to capacity could, we argue, allow a regulatory framework to emerge that enables support for all aspects of legal capacity, rather than only for everyday preferences.

## 5. Conclusions

In this paper, we have demonstrated that the current regulatory approach to capacity in English law (the MCA as it is used in practice) falls short of the requirements for supporting legal capacity under the CRPD. We have shown that the MCA has laid the groundwork for supported decision-making in relation to everyday preferences and some life choices. The MCA approach, which relies on functional capacity assessments, does not provide a framework for supporting disabled people, or empowering care professionals to support disabled people, to make more complex decisions in their everyday lives. We have argued that CRPD compliance will require more than the simple amendment of the MCA to support the will and preferences of the individual within best interests decisions. Instead, we consider that changing law in practice requires change across social, legal and policy domains in order to secure disabled people's rights to support with the enjoyment of their right to legal capacity.

This research, and this paper, focus primarily on the nexus between the CRPD and the MCA in the English socio-legal context. Supported decision-making, and developing CRPD-compliant legal regimes is, however, a preoccupation of many legal academics, disability studies scholars and policymakers across the world. Different jurisdictions approach this issue from alternate perspectives. Some jurisdictions have not yet replaced their guardianship laws, despite ratifying the CRPD; others, like Ireland, have approached the issue by providing a framework that entitles people with cognitive impairments to different levels of support depending on their decision-making abilities. Sweden has already removed the possibility of being legally declared to lack capacity. It is not yet clear which approach to supported decision-making will provide the right balance of empowerment and protection to enable and support the enjoyment of legal capacity by all. The lesson from this research, and the context of the MCA after over a decade in force, is that it has created the conditions to support everyday preferences, but that a focus on testing functional decision-making abilities through capacity assessment encourages a push towards substituted decisions when the decisional context becomes more complex.

Addressing the interlinked strands of social, legal and policy contexts that have woven together to create the regulatory framework for care and capacity under the MCA is not an easy task. The gauntlet thrown down by the CRPD, and especially by the interpretation of the Convention rights by the CommitteeRPD, provides a challenge that all regulatory systems will find difficult to fully address. These Everyday Decisions research project findings show us that legal, social and policy change will all be required before we can ensure that all disabled people are given the support they require to enjoy their legal capacity.

**Author Contributions:** Rosie Harding (R.H.) conceived and designed the research project; R.H. conducted all interviews with disabled participants, and two of the care professional interviews, Ezgi Taşcıoğlu (E.T.) conducted the remaining care professional interviews; R.H. and E.T. analyzed the data; R.H. wrote the paper; E.T. commented on the draft manuscript. Both authors have read and approved the final manuscript.

**Acknowledgments:** This research was funded by the British Academy, grant number MD150026 and the University of Birmingham. The authors would like to thank the anonymous peer reviewers for their helpful comments.

**Conflicts of Interest:** The authors declare no conflict of interest. The funding sponsors had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript, or in the decision to publish the results.

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