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Everyday Decisions Project Report

Supporting Legal Capacity through
Care, Support and Empowerment



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BIRMINGHAM LAW SCHOOL

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We would like to thank all of the organisations and individuals who assisted with the project.

These initial findings will be developed further into academic publications. Links will be provided on the Everyday Decisions website at www.legalcapacity.org.uk.

An easyread summary of the project findings is available on our website.

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EXECUTIVE SUMMARY

The Everyday Decisions project explored how people with intellectual disabilities make everyday decisions in and about their lives, and how care professionals support them in doing so. Our research explored how mental capacity law works in practice to identify areas of good practice and areas where practical changes, shifts in social attitudes or legal reform are needed to secure the rights of disabled people.

Our main legal focus has been on the Mental Capacity Act 2005 and the UN Convention on the Rights of Persons with Disabilities. We were interested in a wide range of life domains, including everyday choices about food and clothing, life choices like housing, education and employment, and difficult choices like financial, medical and legal decisions. We also explored relationship and friendship choices.

We found very many examples of excellent practice across all levels of care and support services. Many of the intellectually disabled participants spoke extremely highly of the services and support they receive from care and support staff, care professionals, family members and peer networks.

KEY FINDINGS

We found that whereas the MCA was well embedded in the professional awareness of care professionals, few had heard of the UN CRPD. Some care professionals stressed the importance of support for people with capacity to make good decisions, not only support in making any decision.

We found that people with intellectual disabilities, including those with quite profound impairments, and limited or no communication were often facilitated to make choices about everyday activities, food, and clothing. Care professionals used a range of strategies to ensure everyday choices were both offered and respected. For those with no verbal communication, multisensory approaches to communication were used to good effect. Care planning was seen by care professionals as a vital aspect of supporting people with disabilities in making everyday and life choices.

Life choices were also often well supported. Intellectually disabled participants reported having control over decisions around education. Most intellectually disabled participants reported undertaking voluntary work, often in charity shops. Most would also like to engage in paid employment, but found very limited opportunities were available to them to access paid employment, and sometimes this was made more complex by the benefits system. Care professionals seldom reported supporting decision-making around education or employment. Decisions around housing were considered more challenging by both care professionals and intellectually disabled people, and were often made more difficult by a lack of choice or availability of suitable accommodation in appropriate locations.

Day to day financial management was an area where people with disabilities were often supported, but also needed help to manage their finances well. Innovations like easyread bank statements made it easier for people with intellectual disabilities to manage their own finances. Participants reported varying levels of support from banks around people with intellectual disabilities managing their own money. When financial power of attorney was discussed in these interviews, it most often arose as a result of experiencing challenges in dealing with banks and financial institutions.

Difficult decisions were less well supported, overall, than everyday decisions or life choices. Most intellectually disabled participants reported being able to make some medical decisions, but often taking a supporter with them to appointments to help them in difficult interactions. Care professionals reported medical decisions often being made using the best interests framework under the Mental Capacity Act 2005, following multidisciplinary best interests meetings. Care professionals also reported being asked to sign consent forms on behalf of service users, or other inappropriate understandings of the MCA by healthcare staff. Frontline care staff often suggested that financial, legal and medical decisions would be made by or through their managers, rather than being discussed directly with the disabled person.

Legal issues associated with future planning (wills, advance decisions, power of attorney) were rarely discussed by intellectually disabled participants. Those who did discuss these issues found them difficult, though expressed a desire for support in thinking through the issues. Care professionals generally reported not being involved in decision-making in these areas. Supported decision-making was uncommon, but did happen in the context of legal decisions in this research.

Most care professionals were reluctant to discuss issues relating to the relationships and friendships of the people they care for. Questions on this topic usually elicited discussion about contact with family members. In contrast, over half of the intellectually disabled participants reported being involved in an intimate relationship, including being engaged, and in long term relationships with a boy/girlfriend. Living in an independent living context (with appropriate levels of support) appeared most conducive to developing intimate relationships and friendships for people with disabilities.

Engagement with disability-focused community activities, particularly those involving the arts (music, dancing, drama, art) and sport were particularly helpful in offering opportunities for people with disabilities to form independent friendships and relationships.

Intellectually disabled participants and their supporters expressed difficulties navigating the system of benefits and sanctions. Some participants found that the payment schedules of benefits made managing money with tools like direct debit more difficult.

Community services aimed at, and especially those run by and with disabled people, like self-advocacy organisations appear to be a vital means through which people with intellectual disabilities can build decision-making skills, access appropriate support for everyday decision-making, and build supportive peer networks. Independent advocacy services were highly valued by care professionals, especially when mediating between service users and their families.

Care professionals sometimes expressed difficulties balancing the regulatory needs of care planning and paperwork with the time required to provide high quality care.

We found that there is a tension between supported decision-making and mental capacity assessment. Sometimes people are found to lack capacity when they might have been able to make their own decision with the right amount of support. Sometimes people are considered to have capacity when they were actually unable to make particular decisions.

OVERALL RECOMMENDATIONS:

1. Whilst there is general awareness of the basics of the Mental Capacity Act, there is scope for ongoing, and potentially more detailed, training for frontline care staff about the importance of supporting decision-making under the MCA as a way of supporting legal capacity.
2. A public awareness raising campaign on the UN Convention on the Rights of Persons with Disabilities might help to increase general understandings of the CRPD within the care sector.
3. Care professionals would both be interested in, and benefit from specific training and continuing professional development on the UN CRPD and generic Human Rights issues.
4. Implementation of the changes to the best interests in the MCA proposed by the Law Commission in 2017 may help to embed supported decision-making more fully in practice, and bring the MCA closer to full CRPD compliance.
5. Intellectually disabled people and care professionals with experience of best practice in supporting legal capacity should be involved in any review and revision of the MCA Code of Practice.
6. Appropriately resourced support services, including self-advocacy groups run by and with disabled people are vital mechanisms for fostering a CRPD compliant culture of supported decision-making for people with intellectual disabilities.
7. Nuanced support and communication approaches, building on strategies developed for everyday and life choices, should be utilised for more complex life choices and legal decisions.
8. More research is needed into how banks and financial institutions engage with customers with intellectual disabilities, effective support frameworks for everyday financial management, and managing bills and payments.
9. More research is needed into how the MCA is used in medical consent processes for people with intellectual disabilities.
10. Given the importance of future planning, further research is required into how best to support people with intellectual disabilities in making wills, advance decisions and granting Power of Attorney.
11. A shift in social attitudes about intellectually disabled people, relationships and friendships is required to better support the relational lives of people with intellectual disabilities, particularly those living in care homes and supported living environments.
12. Policy makers should give serious thought to simplifying the benefits and sanctions regime in order to better support people with intellectual disabilities to enjoy an adequate standard of living and to access their communities.
13. Disabled people's self-advocacy organisations should be funded and supported to provide additional sources of advocacy, support and empowerment for intellectually disabled people that reaches beyond the statutory minimum requirements under the MCA and Care Act 2014.
14. Frontline care professionals must be given time to complete paperwork that does not detract from their practical care giving. Local and central government investment in care services should recognise the need for both high quality care-giving and care planning.
15. The Code of Practice on the Mental Capacity Act 2005 should be revised to take account of developments in practical approaches to supported decision-making and capacity assessment.

1: THE EVERYDAY DECISIONS RESEARCH PROJECT

BACKGROUND CONTEXT

The right to equal recognition of all persons before the law is a long-standing legal principle. People with intellectual disabilities (here understood to include those with learning disabilities, acquired brain injuries, and dementia) have been routinely denied their right to equal treatment before the law. Many jurisdictions have implemented systems like guardianship whereby people with intellectual disabilities have their rights to make decisions about their own lives legally removed from them, on the basis of perceived limitations in their 'mental' capacity.

An international consensus is emerging about the limits of approaches to legal capacity that remove all or some of the individual's decision-making ability. This paradigm shift follows the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), and the associated interpretation of the rights contained therein by the UN Committee on the Rights of Persons with Disabilities (CommitteeRPD). The CommitteeRPD have suggested that supported decision-making processes that foreground the will and preferences of the individual should always be used instead of objective best interest approaches.

Much legal knowledge about mental capacity and decision-making in England and Wales is constructed through legal proceedings in the Court of Protection. 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 engage in relational interaction 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' and 'mental' capacity 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.

RESEARCH QUESTIONS

There were three central questions at the heart of this research:

1. How do people with intellectual decisions make everyday legally-relevant decisions, and how well are these decisions supported by health and social care professionals?
2. How can an alternative legal and theoretical concept of 'capacity' better empower people with intellectual disabilities to make their own legally-relevant decisions?
3. How can equality of treatment and respect for the full legal capacity of people with intellectual disabilities be conceptually and practically achieved?

AIMS & OBJECTIVES

In addressing these questions, the research aimed to:

- Challenge contemporary understandings of the relationship between mental capacity and legal capacity
- Provide theoretical and practical mechanisms for implementing the right to equal treatment under the law for people with intellectual disabilities
- Expand theoretical understandings of law in everyday life as these apply to marginalised actors in contemporary society, through a case study of people with intellectual disabilities
- Help empower those with intellectual disabilities to make their own decisions and inform best practice in decision-making across legal, social welfare and health care contexts

The focus of this report is to set out our emerging findings in response to our first research question. Subsequent academic publications will address the more conceptual questions at the heart of this research.

2: EVERYDAY DECISIONS PROJECT METHODOLOGY

In order to explore connections between legal capacity and mental capacity, the Everyday Decisions Project involved interviews with intellectually disabled people and with social care professionals who have experience of working with and supporting people with disabilities. Across England and Wales, a total of 46 participants took part in the study: 15 disabled people who were supported by 6 supporters, and 25 care professionals. 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.

Following the UN Committee and Convention on the Rights of Persons with Disabilities, this research constructed disability with an emphasis on the **social model of disability**. The social model of disability seeks to shift the emphasis in disability research, practice and support away from understanding disability as a consequence of medical problems or deficits that exist within the individual, and towards focusing on the ways that disability is constructed and in some cases created by exclusionary social practices.

The paradigm of disability created by and through the UN Convention on the Rights of Persons with Disabilities is explicitly emancipatory of disabled people and seeks to improve the rights protection of disabled people by focusing on how to change society to better meet the needs of disabled people, rather than changing disabled people to better meet the needs of society. In this report, we do not describe the specific intellectual disabilities or diagnoses of our participants. There are two primary reasons for this: first, as the interview sample is relatively small, it may be possible to identify individuals as a result of their diagnosis or impairment; second, by not focusing on the impairments that individual participants experience, we seek to focus on their capacity, capability and self-construction, rather than on their incapacities or limitations.

INTELLECTUAL DISABILITY

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. The UN CRPD often refers to **psychosocial disabilities** alongside intellectual disabilities. Psychosocial disabilities include mental health problems and other psychiatric issues. We did not include psychosocial disabilities in this project, as the issues associated with psychosocial disability are often quite distinct from the issues raised by learning disability, brain injury and other intellectual disabilities. This research did not, in particular, engage with issues raised by the Mental Health Act 1983 (as amended). There are, however, some commonalities in the recommendations we make in this research that might have relevance to people with psychosocial disabilities.

Fifteen intellectually disabled participants participated in interviews about their lives. Interviewees had a wide range of disabilities and impairments. All had some verbal communication skills, though many participants were helped in their expression and communication in the interviews by their supporters. 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 before the empirical components of this project began. Disabled participants were recruited mainly through gatekeeper organisations, and we also used the project’s blog and Twitter account to supplement gatekeeper recruitment.

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 more difficult decisional contexts like finances, relationships and families, and medical decisions. 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. A supporter was involved in 80% (n=12) of the interviews.

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%). Participants lived in a range of different housing contexts: 5 participants lived independently, 6 in supported living environments with varying degrees of independence, 3 with their families, and 1 in a care home. Demographic information about the age range, gender and living arrangements of the participants is represented in figures 2.1 and 2.2.

Figure 2.1: Age and Gender, Intellectually Disabled Participants (IDP)

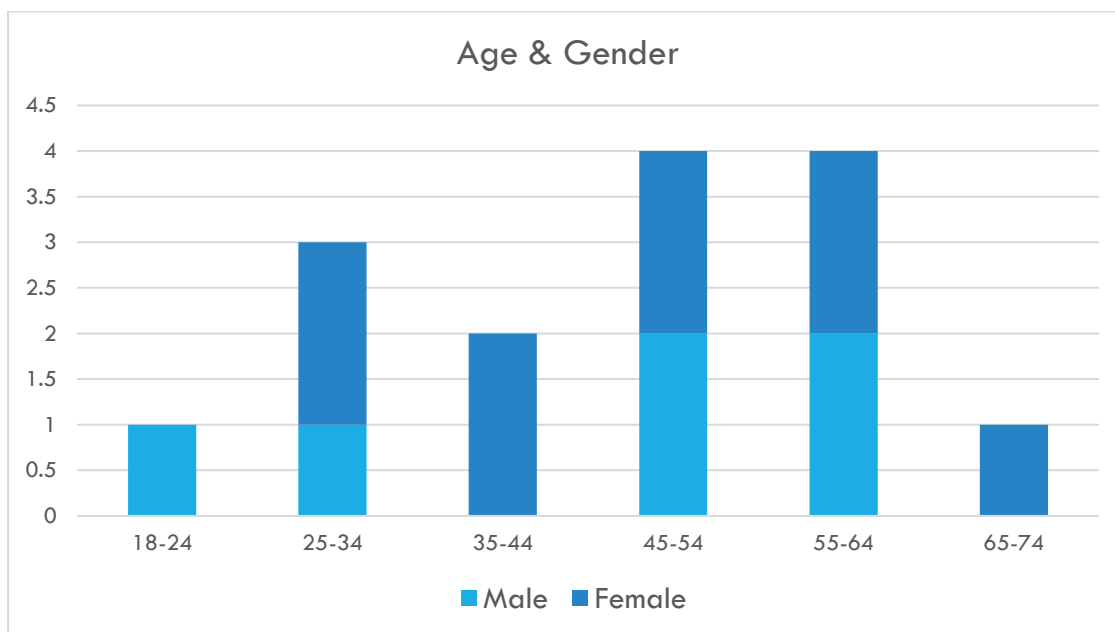
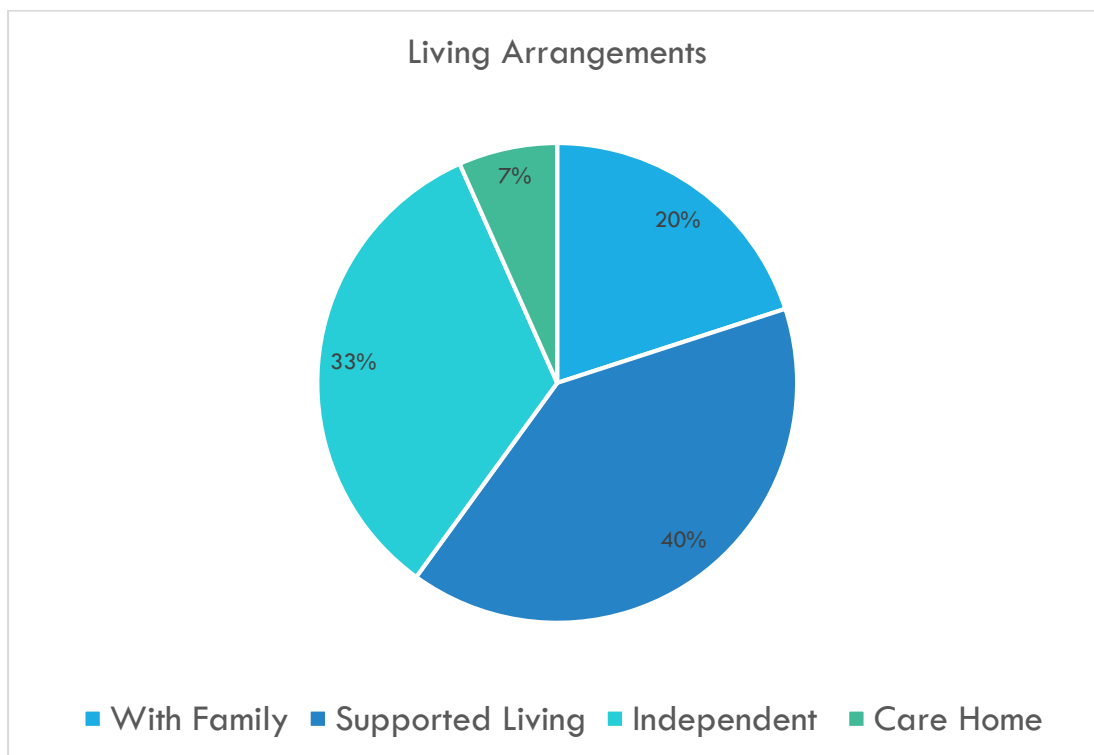


Figure 2.2: IDP Living Arrangements



SOCIAL CARE PROFESSIONALS

We conducted semi-structured, in-depth qualitative interviews with 25 social care professionals who held diverse roles in the care of people with intellectual disabilities. These interviews covered a series of topics, including experiences of working with people with intellectual disabilities, of supported decision-making and of the Mental Capacity Act 2005. Social care professionals were recruited through an opt-in, open recruitment process, using the project’s blog and Twitter account. We also sent letters to a randomly selected sample of 100 care homes in the Midlands (including both East and West Midlands) to seek volunteers from care home staff and management.

Out of 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=3), support workers (n=9) 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-£14,999 to over £50,000.

Figures 2.3-2.5 provide a breakdown of the demographics for the social care professionals who took part in this study.

Figure 2.3: Care Professional Geographic Location

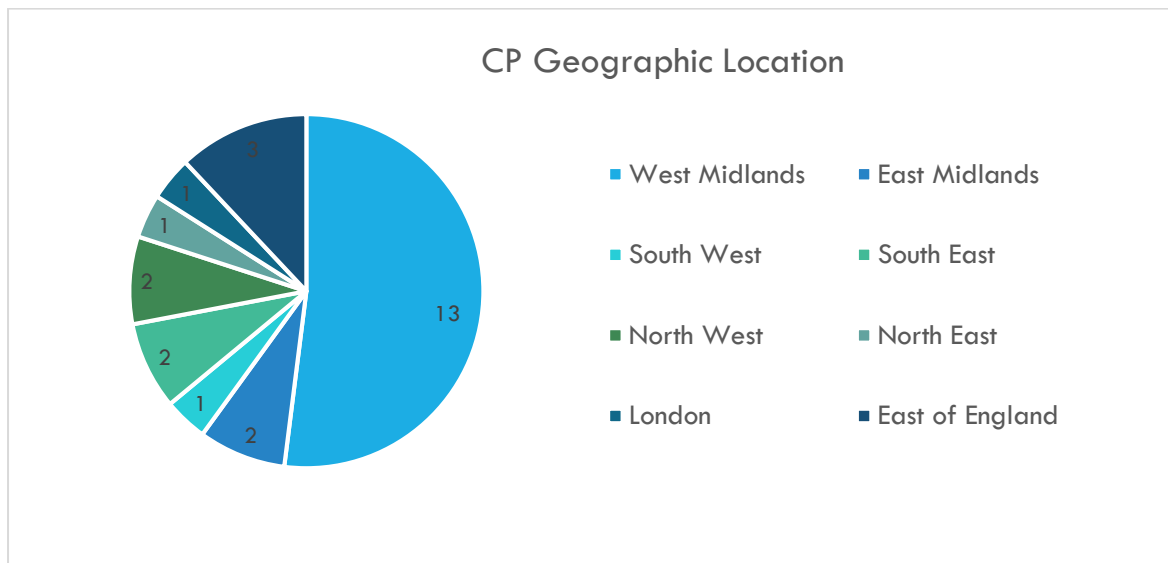


Figure 2.4: Care Professional Gender, Age and Ethnic Group

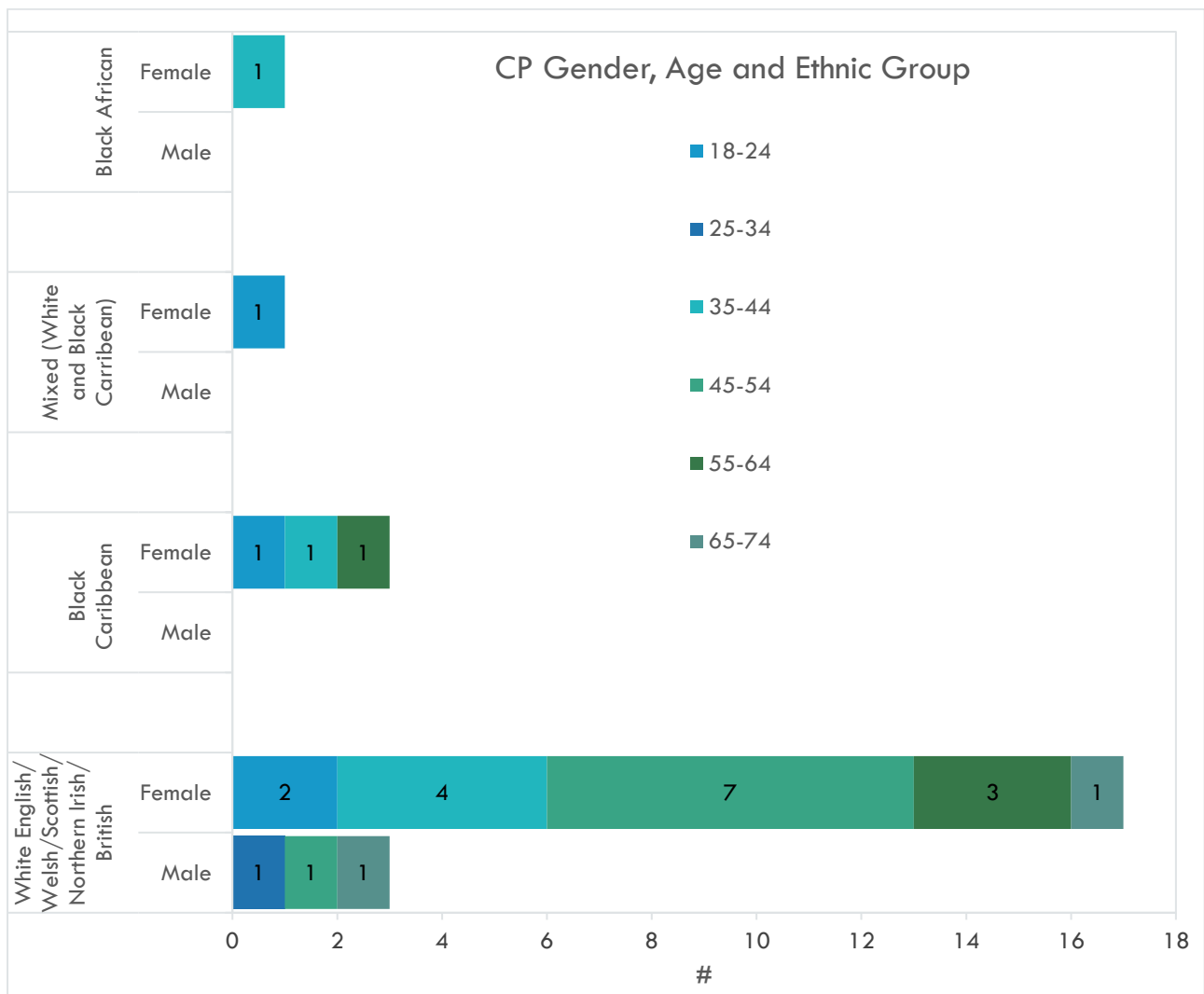
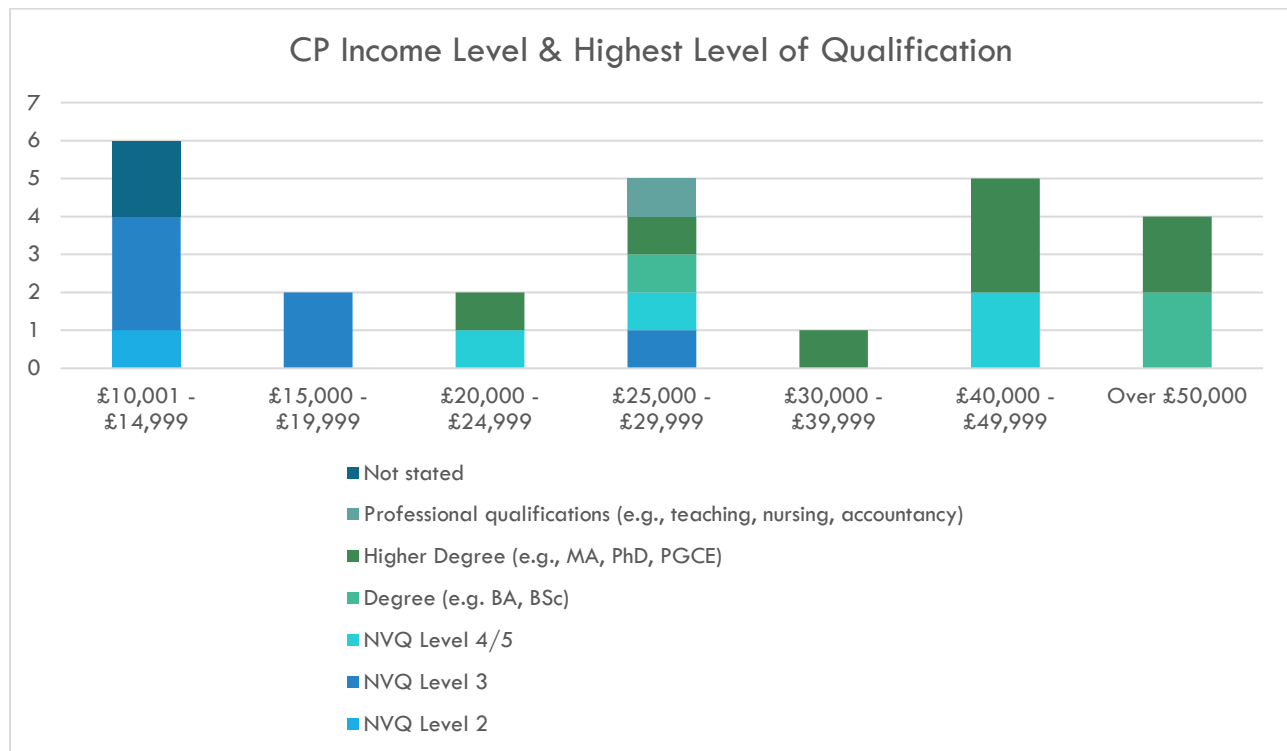


Figure 2.5: Care Professional Income Level and Highest Level of Qualification



3: CAPACITY LAW AND HUMAN RIGHTS

The main legal frameworks that underpin this research are the Mental Capacity Act 2005 (MCA), and the UN Convention on the Rights of Persons with Disabilities (UN CRPD). These legislative frameworks were not asked about directly in the interviews with intellectually disabled people, but several questions about training about and awareness of the Mental Capacity Act 2005, the UN CRPD and generic 'human rights' for disabled people were asked during the interviews with care professionals.

MENTAL CAPACITY ACT 2005 (MCA)

Mental capacity refers to the ability to make decisions. The MCA protects anyone who finds themselves unable to make their own decisions as a result of an impairment of the mind or brain.

The MCA is based on five principles:

- There is a presumption of capacity (s. 1(2)). This means that everybody must be treated as if they have capacity unless or until it is proven otherwise. Under the MCA, the civil standard of proof (the balance of probabilities) is used.
- A person is “not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success” (s. 1(3)). This means that people with impaired capacity are entitled to support to make decisions.
- A person is “not to be treated as unable to make a decision merely because he makes an unwise decision” (s. 1(4)). This means that people should be allowed to make their own decisions, even if considered unwise by others, as long as they have the capacity to do so. This protects the autonomy rights of people with impaired capacity.
- If it is established that a person lacks capacity, then everything done for or on behalf of that person must be in their best interests (s. 1(5)).
- Any acts done or decisions made on someone’s behalf must be done or made in the least restrictive way available (s. 1(6)).

A lack of capacity cannot be assumed based on someone’s appearance, age or other characteristics (s. 2). In order to assess whether someone has capacity to make their own decisions, it must firstly be established whether someone has ‘an impairment of, or a disturbance of, the mind or brain’. This is sometimes referred to as the ‘diagnostic test’, but it does not require a medical diagnosis. Impairments may be temporary or permanent.

Capacity under the MCA is decision-specific. This means that people with impaired capacity might have the ability to make one decision (e.g., what to buy in a shop), but not to make another, more complex decision (e.g., managing complex financial investments).

The MCA uses a functional test to determine capacity (s. 3):

“a person is unable to make a decision for himself if he is unable—

- (a) to **understand** the information relevant to the decision,
- (b) to **retain** that information,

- (c) to **use or weigh** that information as part of the process of making the decision, or
- (d) to **communicate** his decision (whether by talking, using sign language or any other means).”

Section 3 further specifies that the information relevant to the decision can be given in a simplified form, and need not be retained for long periods, but does include the **reasonably foreseeable consequences** of making or not making the decision.

It is important to note that the MCA does not apply to decisions regarding marriage or divorce, voting, consent to sexual relations, or the making of an adoption order. In all other domains, decisions which are made on behalf of persons lacking capacity must be made in their best interests. The Supreme Court have clarified that the perspective of the person who lacks capacity should be at the core of best interest decision making.ⁱ

All of the care professional participants in this research showed awareness of the basic principles of the MCA, even if not all could articulate them clearly in terms of the Act itself. There was a significant focus on supporting individual choice from frontline care staff, whether in relation to food, activities, or other day to day preferences. This research uncovered a great deal of excellent supported decision-making practice in all areas of social care.

Most reported having undertaken training specifically in the MCA, and participants who worked in more senior roles (Brain Injury Case Managers, Occupational Therapists, Care Service Managers, Social Workers, Best Interests Assessors and Capacity Assessors) all demonstrated an in-depth, practical, working knowledge of the MCA. Most participants were generally positive about the changes in their professional practice that have been catalysed by the MCA, particularly those who remembered working under the previous legislative regime.

I think its intentions are fantastic. In that sense, it's a wonderful change. Because I do remember the previous regime which was the Mental Health Act and you were either capacitous or were not. You were either a patient or not and I mean, I was brought up with that and I kind of went along with it. In retrospect that was ridiculous but at the time that was how we did things. (Andrew, 65-74, Mental Capacity Assessor)

Not all of the reflections on the MCA were entirely positive about the impact, with particular concerns expressed around the challenges of the Deprivation of Liberty Safeguards (DoLS), especially following the *Cheshire West* decision. Another issue that was raised by some participants, and echoes findings from the House of Lords Select Committee Review of the MCA,ⁱⁱ was a concern that the MCA has been used to deny services to vulnerable individuals:

So to answer your question has it made a difference, it's made a lot of paperwork! It creates a huge amount of delay. It's made some people very rich. I think it has been used as an excuse to deny people services. I think it has been greatly misunderstood. (Adrian, 45-54, Brain Injury Case Manager)

I think a lot of the time there's perhaps an assumption that if you're deemed to have capacity you're deemed to be able to make the right decisions on your own. Whereas actually sometimes, and that's within the Mental Capacity Act as well, you need support alongside you to be able to help you weigh up those decisions. (Angela, 45-54, Brain Injury Case Manager/Occupational Therapist)

We provide a more in-depth discussion of how supported decision-making works in practice in part 5.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (UN CRPD)

In 2006, the UN adopted the final text of the CRPD. The UK Government signed and ratified the CRPD in 2009, and is therefore bound by its provisions.

The CRPD sought to catalyse a 'paradigm shift' in the ways that the human rights of disabled people are understood. The CRPD includes rights relating to every aspect of life. It includes civil and political rights that are familiar from previous international treaties and conventions, like the right to life (article 10), the right to liberty and security of the person (article 14), freedom from torture or cruel, inhuman or degrading treatment (article 15), respect for privacy (article 22), and respect for home and the family (article 23). Alongside these, there are important new protections specifically targeted at improving the lives of persons with disabilities, including the right to equal recognition before the law (article 12), freedom from exploitation, violence and abuse (article 16), living independently and being included in the community (article 19). Finally, the CRPD includes provision about a wide range of economic, social and cultural matters, including rights relating to education (article 24), health (article 25), employment (article 27), social protection (article 28), and participation in public, political (article 29), cultural and social life (article 30).

The rights enshrined in the UN CRPD are highly relevant to this research. Whilst much of the research focused on issues of capacity law, and therefore Article 12 (see further, Chapter 4) of the CRPD, it is vital to recognise the interlinked and mutually supportive nature of human rights protections. Legal frameworks that support the right to equal recognition before the law are worthless if individuals are denied access to the community, suffer exploitation, violence and abuse from known or unknown others, or have no support to participate in education, employment, public, political, cultural or social life.

As this research was underway, the CommitteeRPD published its concluding observations on the UK's initial report concerning the CRPD. The report included a large number of recommendations, including that the UK should reform the current law relating to mental capacity and mental health, as it does not fully respect the Article 12 rights of persons with disabilities, and "step up efforts to foster research, data and good practices of, and speed up the development of supported decision-making regimes".ⁱⁱⁱ This research provides further evidence of the desirability of using supported decision-making to empower disabled people.

In contrast to the MCA, the participants in this research generally showed very little awareness of the CRPD, or the potential relevance of it for their practice. In the care professional interviews, just 6 interviewees expressed positive awareness of the CRPD, and had any sense of the focus of the Convention. Of those, two were aware of potential gaps in the implementation of the CRPD in the UK:

I've heard of [the CRPD] on training courses. I know that Britain's not very compliant with it, and I think that how our practice on the ground fits with that is currently fairly tenuous really. (Claire, 45-54, Regional Manager, Brain Injury)

One participant expressed reservations about the CRPD, and particularly about the CommitteeRPD's interpretation of Article 12 set out in General Comment 1:

The people who drafted that had never interacted with my patients who have had very severe, traumatic brain injuries and are absolutely unable to make even very simple day-to-day decisions without tremendous amounts of support. In fact the amount of support is often so much that they're not really supported decisions, they're decisions being made by someone else if we're honest. (Andrew, 65-74, Mental Capacity Assessor)

Whilst this was very much a minority view, it captures an important kernel of truth in the way that supported decision-making, mental capacity and intellectual disability intersect in everyday life. As will become apparent in part 5, whilst many care professionals were happy to support everyday choices, more meaningful life choices and legal decisions were more commonly considered under the realm of best interests. Moving away from this approach towards the new paradigm of disability equality mandated by the CRPD and CommitteeRPD will require creative responses aimed at shifting societal and professional attitudes towards disability.

HUMAN RIGHTS

Whilst no direct questions were asked about the Human Rights Act 1998 (HRA) in the research, most participants had a general awareness of the importance of human rights in care and support settings. In general, most care professional interviewees considered that human rights were important in their practice, but articulation of the specific content of legally enforceable human rights was not clearly apparent. Instead, participants generally focused on basic understandings of universal humanity, non-discrimination and choices and freedoms.

For those participants working on the front line of care and support services (care and support workers, senior care workers and team leaders) human rights were generally characterised as being about treating others with respect, and supporting choices.

The human rights, it's about humans having rights, it's exactly what it says. They have their rights to do what they want when they want, and we don't stop that. If they want to do something they can do something. So it is very good to let them do what they want, it's their rights as a human. (Sophie, 18-24, Kitchen Assistant)

I think everybody has a right to make their own decision in life really. I know some need a bit more support and a bit more guidance. (Lily, 18-24, Senior Care Assistant)

I think human rights is always present in our everyday practice. Because the rights of the clients, the staff yeah, it's always at the forefront of what you do. You want to make sure that you're doing the things that are right. You're not biased and you know the clients that you're working with, the staff that you're working with. (Jennifer, 35-44, Care Home Team Leader)

Those in more managerial roles were sometimes less convinced about the importance of human rights in their everyday practice. For example, Lucy talked about translating legal ideas into more acceptable language for her staff:

My staff don't want to hear the Human Rights Act or data protection. It is about "OK, come on then, in best interest we'll make that decision," and "don't forget to put that file away because of confidentiality." So it's simplifying it down to my staff by using that terminology, if you like.
(Lucy, 35-44, Care Manager)

Under the Care Act 2014, the vast majority of care services will now be considered to be exercising a public function in the delivery of care. Failure to respect the rights of service users under the HRA could lead to legal liability for rights infringements. As a result, it is important that all care staff are aware of their responsibilities regarding protecting and supporting the rights of service users and clients.

CAPACITY LAW AND HUMAN RIGHTS - RECOMMENDATIONS:

- 1. Whilst there is general awareness of the basics of the MCA, there is scope for ongoing, and potentially more detailed, training for frontline care staff about the importance of supported decision-making under the MCA as a way of supporting legal capacity.**
- 2. A public awareness raising campaign on the UN Convention on the Rights of Persons with Disabilities might help to increase general understandings of the CRPD within the care sector.**
- 3. Social care professionals would both be interested in, and benefit from, specific training and continuing professional development on the UN CRPD and generic Human Rights issues.**

ⁱ Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67

ⁱⁱ House of Lords Select Committee on the Mental Capacity Act 2005, Report of Session 2013-14, 'The Mental Capacity Act 2005: post-legislative scrutiny'. Available at:
<http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf>

ⁱⁱⁱ Committee on the Rights of Persons with Disabilities 'Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland' CRDP/C/GBR/CO/1, 3 October 2017, at [31]. Available at:
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>

4: CAPACITY

The Everyday Decisions Project research focused on legally relevant decision-making by and with people with intellectual disabilities. In this part of the report, we outline the ways that disability and capacity were conceptualised in the research project.

CONCEPTS OF CAPACITY

A significant element of the Everyday Decisions project has been a focus on disentangling the two distinct, but related, concepts of **Legal Capacity** and **Mental Capacity**.

Legal capacity: the formal ability to hold and to exercise rights and duties. Everyone has a right to legal capacity.

Mental capacity: the decision-making skills and competencies of a person. Mental capacity varies from person to person.

Article 12 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) reaffirms disabled people's rights to 'equal treatment under the law'. This includes "the right to recognition everywhere as persons before the law" (Article 12(1)), and recognition that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" (Article 12(2)). The UNCRPD also requires that States Parties (that is, countries that have signed and ratified the convention, including the UK) provide "access by persons with disabilities to the support they may require in exercising their legal capacity" (Article 12(3)) and "safeguards to prevent abuse", which "ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free from conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible, and are subject to regular review by a competent, independent and impartial authority or judicial body" (Article 12(4)). The Committee on the CRPD clarified how Article 12 should be interpreted in their first General Comment.^{iv}

The denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.^v

Legal capacity is a reasonably straightforward legal concept. Legal capacity is an important part of the fundamental human right to equal treatment under the law. If someone is not fully recognised as a person before the law, this is an infringement of their basic, fundamental human rights. Legal capacity is not, however, a mere status right. Legal capacity should also be "enjoyed" by people with disabilities. To "enjoy" legal capacity means more than simply to be recognised as a person before the law. It also includes the right to do things. To make choices that are respected by law. To be an actor under the law.

Legal capacity is therefore understood quite differently from the idea of ‘mental capacity’. Just as some people need support to make decisions (as required by and supported under the Mental Capacity Act 2005), some people need support to enjoy their legal capacity. Support to enjoy legal capacity can be given in many different ways, some founded on simplified communication, some based in the appointment of people to help with decision making, like attorneys, deputies, and advocates. Support to exercise legal capacity is a human right protected by the UN CRPD, which means that State Parties have a responsibility to provide access to support.

It is very important to remember that support with the enjoyment of legal capacity should mean support (not ‘best interests’, coercion or restraint). People with impaired mental capacity have often had all of their rights to enjoy legal capacity taken away from them on the basis of their decision-making skills. Legal frameworks like full guardianship prevent people from making decisions for themselves, even if they do have the mental capacity to make a particular decision. Guardianship laws still exist in many countries worldwide.

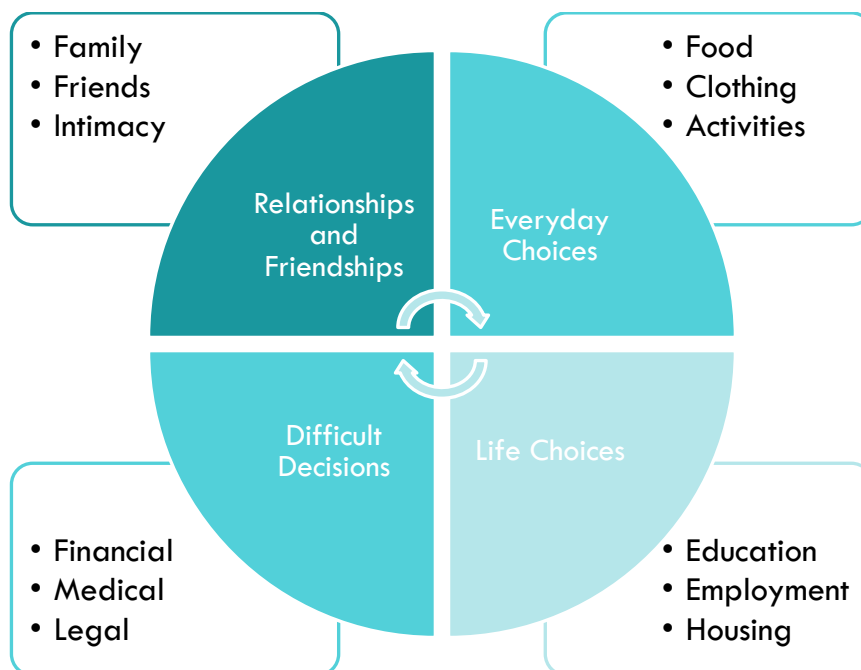
The Mental Capacity Act 2005 assesses capacity on a decision-specific basis, and uses a functional test to ascertain whether a person with an impairment of the mind or brain has the capacity to make a decision. If the person fails the functional test, then another person can make a decision in their ‘best interests’. Recently, the Law Commission suggested that English law relating to best interests decisions should be changed, because the current approach to ‘best interests’ in the Mental Capacity Act 2005 gives insufficient priority to the wishes and feelings of the person who is at the heart of the decision.^{vi} The findings from this research project give further weight to the case for law reform in this area.

SUPPORTING LEGAL CAPACITY

The Everyday Decisions Project found that everyday decisions under the Mental Capacity Act can be split into four broad categories: Everyday Choices, Life Choices, Difficult Decisions, and Relationships and Friendships (see Figure 4.1). Part 5 provides detailed analysis of the ways that disabled people and care professionals expressed their experiences of decision-making in each of these domains. There are, however, some general points about supported decision-making that cut across all of these decisional contexts.

In general, we found that disabled people felt they had significant control over everyday decision-making, and also that they were generally well supported in making life choices in many different areas. Some ‘life choices’ decisions, notably those around housing, were more challenging, in part because choices were dependent on external factors (e.g., the availability of suitable placements and/or properties, or the need to pay ‘bedroom tax’ in larger properties).

When the level of decisional complexity increased, such as where people were required to make complex financial, medical or legal decisions, disabled participants expressed less certainty about decisions, and greater needs for support. In contrast, care professionals often defaulted to substituted decisions made in the persons best interests in these areas. Finally, whereas decisions and choices around relationships and friendships were seen as very important to disabled participants, many social care professionals appeared uncomfortable discussing this aspect of disabled people’s lives. When asked questions about supporting relationships and friendships, most care professional participants focused on issues to do with family relationships, rather than friendships with peers or intimate relationships.

Figure 4.1 Decisional Contexts in Supporting Legal Capacity

Despite the variation across decisional contexts, both intellectually disabled participants and care professionals shared important insights in to how supported decision-making happens in practice. This wealth of experience, built up in daily care and support contexts since the MCA came into force in 2007 should be drawn upon when the MCA Code of Practice is revised.

The Everyday Decisions research project found that effective supported decision-making rests on a wide variety of techniques, systems and scaffolds, which come from a range of areas. Participants in this research stressed the importance of communication, advocacy and self-advocacy, and community engagement in supporting legal agency and legal capacity.

Communication in this context requires time, space, repetition, simplification and the use of multi-sensory methods. Advocacy and Self-Advocacy organisations were considered vitally important in supporting intellectually disabled people to express their views and perspectives, to build decision-making skills, and to generate relationships and peer networks. Finally, opportunities for community engagement, in the form of arts, games, sports, working and learning were all considered to be extremely important contexts for supporting people with intellectual disabilities to enjoy their rights to legal capacity.

SUPPORTING LEGAL CAPACITY - RECOMMENDATIONS:

- 4. Implementation of the changes to the best interests in the MCA proposed by the Law Commission in 2017 may help to embed supported decision-making more fully in practice, and bring the MCA closer to full CRPD compliance.**
- 5. Intellectually disabled people and care professionals with experience of best practice in supporting legal capacity should be involved in any review and revision of the MCA Code of Practice.**
- 6. Appropriately resourced support services, including self-advocacy groups run by and with disabled people are vital mechanisms for fostering a CRPD compliant culture of supported decision-making for people with intellectual disabilities.**

^{iv} Committee on the Rights of People with Disabilities (2014) General Comment No. 1 on Article 12: Equal recognition before the law CRPD/C/GC/1. Available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>.

^v CRPD/C/GC/1 at para 8.

^{vi} Law Commission *Mental Capacity and Deprivation of Liberty* (Law Com no 372, 2017)

5: SUPPORTING DECISION-MAKING IN EVERYDAY LIFE

EVERYDAY DECISIONS: FOOD, LEISURE, ACTIVITIES

Support provided to disabled people for day-to-day decisions featured prominently in the accounts of care professional participants. These decisions included preferences such as about what to eat, what to wear, what sort of activity to take part in or where to go on holiday. The most common approaches undertaken to support for this kind of daily decisions were:

- **narrowing down choices** (e.g., rather than asking the person an open question about what they want to eat, presenting them with a restricted number of choices),
- **providing context/memory** and jointly generating pros and cons about the decision that needs to be made (e.g., reminders about the weather to a person choosing their clothing for the day),
- **establishing structures** to help individuals execute their decisions in a way that also leaves room for flexibility (e.g., at a time scheduled for an activity in the sensory room, asking the person whether they want to do that or not, and supporting them for another activity like going to the garden to play some games if they prefer to do so.)

One care professional participant very aptly referred to these structures as ‘scaffolds’. These scaffolds take many forms and formats, and include spatial and temporal elements and material and relational resources. They can be temporal and gradually lifted, or may be needed on a continuous basis depending on the particular circumstances of the supported person and the kind of decision that’s being made.

Examples of supported decision-making in the context of everyday life show the centrality of communication in supporting intellectually disabled people. Supporters use a wide range of communicative tools; verbal, visual and non-verbal, and they also 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, complexities and the intensive labour that goes into supported decision-making, below are three different examples of how care professionals tailored the form of the support to the person’s communication and decision-making style:

You have to word things differently. Because 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, 45-54, Care Manager)

What Julia called here the need to ‘word things differently’ was voiced by many other social care professionals as the need to formulate questions differently, to find the connections, to allow the person to take over the interaction, and to search for other methods of verbal interaction to provide support to the disabled person in line with their communication as well as their decision-making style.

Adrian and Leslie, on the other hand, shared examples of how the process of decision making possesses possibilities beyond verbal communication. Adrian’s account on the support they gave to a disabled person to have a shower when he found it difficult to translate his expressed wishes to shower with the action of doing so shows how supported decision making can be conveyed through an organisation of the 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. [...] The shower, 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, 45-54, 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 he wouldn’t have, if you took him somewhere like Blackpool, for instance, I don’t like Blackpool, but if you took him somewhere like Blackpool, he wouldn’t actually enjoy that because it would be too loud. It would be overstimulating. He’d find it quite chaotic as a place. Whereas if he’s in the country and he’s walking, it’s beautiful and pretty and it’s quiet and it’s tranquil, he loves that, and he’ll just walk and walk and walk and he’s very happy. But that’s more about sort of trial and error over the years of trying different things, because he hasn’t got the ability or the capacity to choose those sort of things. [...] 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. [...] So 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, 35-54, Care Manager)

Overall, all 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. Individualised 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 offering, channelling, transmitting and facilitating supported decision-making.

Experimentation is also an important element in developing communication strategies to support decision making. Such experimentation relies on years of experience, extensive periods of working together 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.

The accounts of care professional participants suggest that ensuring disabled people have control over their daily decisions is considered key to individuals' autonomy. Encouraging and supporting disabled people to pursue activities and interests beyond those considered to be their basic needs appears 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. I do quite, I did about five hours last week, I sometimes do three hours, and sometimes I do two hours. (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 education 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. Many of the disabled participants in this research were involved with self-advocacy groups. Self-advocacy disability groups 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 organisations, which are run by and for intellectually disabled people appear key to effective supported decision-making in law and society.

LIFE CHOICES: EDUCATION, EMPLOYMENT, HOUSING

EDUCATION AND EMPLOYMENT

As with everyday decisions, many of the intellectually disabled participants in this research found that they were quite well supported in decisions around education and, to a lesser extent, employment. Several participants spoke of attending college, either at the present time or in the past, with mixed levels of success. Where educational opportunities aligned well with the preferences and interests of disabled people, they spoke about them as a positive force in their life. James, for example, studied arts, fashion and music technology at college, which he found to be a very positive and rewarding experience. Where educational opportunities were not well aligned with wishes and preferences, disabled participants reported less positive experiences. Amanda, for example, didn't 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 more 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 education contexts would allow people with disabilities to continue in education longer, providing greater future employment opportunities.

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)

Most 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.

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, employment and education opportunities appear limited for intellectually disabled people, though all of these participants enjoy the voluntary work that they do, and would like more opportunities for suitable paid work.

HOUSING

Though we have categorised housing decisions as a ‘life choice’, making choices around housing was one of the areas which care professional participants considered that disabled people have little choice. In many cases, housing decisions are made following assessments by social workers, providers and families. These decisions are also constrained by limitations on choice as a result of insufficient funding and lack of accessible and affordable housing for disabled people. For care professionals, it can take a lot of negotiation with local authorities to secure suitable housing for the disabled people they work with. Access to support and advocacy are also of crucial importance in decisions by disabled people to live in a place of their choice, especially when they want to move out of their family home to live on their own and pursue an independent life.

Leslie, a care home manager described a positive change in the post-MCA period about the way that housing decisions of disabled people are made. Compared with the earlier moves of residents into her care home when “sadly there was no real input or decision within that”, she told how people who moved in more recently were given a chance to make a decision about their accommodation:

So with them there was actually- the discussion took place. 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, 35-44, Care Home Manager)

Intellectually disabled participants also expressed frustrations with some elements of securing appropriate accommodation, and problems, difficulties and challenges associated with living in places that were not suitable for them.

Rebecca, for example, told of having been financially abused by her previous neighbours, who she described as “drug addicts”:

Rebecca: And she’s really good neighbour. Before I had horrible neighbours.

RH: Did you?

Rebecca: I used to be in a flat. It was [street name], and I had a horrible neighbour. And they took money off me.

RH: Really?

Rebecca: Yeah, and they were supposed to be my friends.

RH: That’s not very good, is it?

Rebecca: No.

RH: So, what happened about that?

Rebecca: One day I kept it quiet. One day I kept it really quiet, didn’t I? And I wouldn’t tell. And I got upset about it. And because she took the crisis loan off of me: £69. And they were drug addicts.

RH: Oh, that’s awful.

Rebecca: And I thought right I must do something about it. And I told you [to supporter] in the end, didn’t I? I wasn’t going to tell, and I had to go to court about it.

RH: Did you? That must have been difficult.

Rebecca: But I went, was it twice? And after that I moved.

Rebecca’s experience underscores the challenges associated with finding appropriate housing or placements for disabled people. Independent living within the community requires suitable properties to be found, where intellectually disabled people are not placed at increased risk of harm or abuse. Other intellectually disabled participants told of long delays in finding suitable accommodation, and of waiting for long periods for a suitable property to become available. Michelle, for example, had to wait over two years for an appropriate property to move away from a shared supported living context that she was finding stressful.

Similarly, Tracey had been looking for accommodation closer to the town centre. She wanted to move to be more central because of her mobility impairments, but her need for a ground floor property, alongside the added complexities of the ‘bedroom tax’ mean that she has been unable to find a suitable property to move to.

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)

I wanted to [move house] 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. (Michelle)

The contemporary limitations posed on housing choices for individuals reliant on state support (the 'bedroom tax' and changes from housing benefit to Universal Credit) are also compounded for people with intellectual disabilities. Finding a suitable property though 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.

DIFFICULT DECISIONS: FINANCIAL, MEDICAL, LEGAL

FINANCES

Support in decisions around small scale day-to-day expenses reported by care professionals were very similar to those in other daily decisions: identifying needs of disabled persons, narrowing down their choices, and jointly generating pros and cons about their options. Few disabled people whom care professional participants work with had direct access to their money and most of their major financial affairs were dealt with either by court appointed deputies or through care home management.

A few examples of support given to develop financial skills demonstrate how intellectually disabled people can be assisted to gain control over their finances. These examples include building structures of support which rely on creating mirror environments, using shopping lists, schedules and other environmental resources to enable gradual building up of such skills.

Patricia, for example, told how she supported a brain injured person with a dependency on cannabis to gain control of his spending and living by making his money dependent on engaging with daily tasks and activities. Each task he completed would earn him a proportion of his weekly finances. By rationing his income in that way, the support allowed him to both engage more with the community, and also to reduce his cannabis use:

He did stick with it indirectly. He tried to challenge me all the way and I think because he was having that banter and that battle ... but he did engage and sometimes ... he got £40, sometimes he got, you know, a little bit less, but that then curtails how much cannabis he was taking in a week, it was less and he was managing. So we saw a different type of client. ... [He] was now showing signs of potential that he could live with minimum support independently. (Patricia, 35-44, Senior Case Manager)

Support with developing financial independence was also very important as a mechanism for disabled people to protect themselves from financial abuse. Gareth told us a story about being taken advantage of by a previous personal assistant. He said that it started with her taking him out shopping and asking him to pay for things for her at the till because she didn't have any money on her, and taking advantage of his good nature, and the complexities of social interaction.

The crafty bit was when you get to the till. You're in the queue, you've got to the till, you're standing at the till, crunch, they haven't got money. So hang on you haven't got money, you want this, what are you expecting me to do? Of course, you can guess what would happen. On my card. (Gareth)

Gareth didn't realise at first what was going on, but then a friend of his had the same person working for him and asked Gareth if he'd had problems with her. Gareth and his friend were both supported to confront the personal assistant, who "resigned from her job, guilty conscience. She just walked" (Gareth). Since then, and with support from a new personal assistant, Gareth has taken more control over his financial affairs, and now gets an easyread bank statement so that he can see what's going in and out and better keep track of his finances: "I can go out and enjoy myself now more than what I ever used to do before. And that's a total difference" (Gareth).

Gareth's story demonstrates why supported decision-making is potentially more empowering than substituted decision-making for people with intellectual disabilities. Where people are not given the support and scaffolding to have awareness of their financial affairs, they are less able to protect themselves from financial abuse. Whilst not all people with disabilities can be fully supported towards financial independence, innovations like easyread bank statements are important support tools that help scaffold people towards relative independence.

MEDICAL

When it comes to medical decisions, the examples we gathered through care professional interviews usually revolved around best interest decisions. Several care professionals raised the issue of health services justifying non-intervention by presuming capacity or incapacity and by refusing to listen to the carers. There were also instances where care staff described being asked to sign consent forms on behalf of service users.

All my staff are terrified of every time they have to take a service user to the hospital they're always going don't sign anything, make sure you don't - because the hospitals are still very keen on we need consent: there's the form, sign it. Yet the Mental Capacity Act has been out for what, 12 years now, and they still try and get us to sign to say that we would all consent on their behalf and it's frustrating, but all my staff are aware that they under no circumstances they consent to anything, and again that obviously the decision maker then is whoever says what they need to do. But generally everything is, unfortunately it's done with best interest. (Julia, 45-54, Care Manager)

A good example of supporting a medical decision by a care professional was about a woman with a brain injury who has very low muscular tone which puts her at risk of falling. Instead of "forcing her" to have an anterior cruciate ligament surgery which she didn't want to have or "walking away", Adrian devised a support structure to have her what she wants – not to have surgery – through regular exercising to strengthen her knee muscles. This structure consisted of enabling her active participation into the process of setting the goal and the plan for the execution of the decision. This involved Adrian sending her text messages as well as recruiting the husband who wants her to have the surgery into the support structure to prompt her to do the exercises.

The intellectually disabled participants managed medical decision-making in a range of different ways. For many, a key way of ensuring that they were supported in their medical decision-making was to attend medical appointments with either a member of their family or a paid support worker.

Tracey: They explain in big words, and I never know what big words are. Some of the big words they say and I'll say excuse me what do you mean? And they explain it. But sometimes they don't explain right. And I don't go doctors very often as it is.

RH: Can you give me an example of when the doctors aren't explaining things and how that makes you feel?

Tracey: Well it makes me feel frustrated and angry, because then I go home and I sit at the computer and I look it up on the computer. And when I find out what it is I say "ah yes, I do know about that."

As the accounts from both Gareth and Tracey demonstrate, one of the main problems that people with intellectual disabilities experience with medical appointments is that the treatment or issue is not always explained in the most accessible way possible. Extra attention to decision-making support, using simplification, scaffolding and other supported decision-making tools could help empower intellectually disabled people to engage more fully with medical decision-making.

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)

Some intellectually disabled participants had formalised their support needs in the form of a health and welfare power of attorney. Alex, for example, gave an example about always wanting to have his mother with him when he went to medical appointments:

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. So in that sense, I mean last week, in fact last Friday ... I'd got a bad tooth and I've had earache and everything. And he wanted to do root canal treatment and I hadn't got a clue. So my mum who was sat in the corner, I asked her to explain it to me. And she, even though I come across as very confident I struggle in that sense. ... 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. But normally I haven't got a problem in saying how I feel (Alex).

Similarly, Carrie had health and welfare power of attorney put in place because she wanted to ensure that if anything happened to her parents (whom she lived with) she would not be placed in a care home.

I mean like one of my friends went into care and I said I'm not going into care, not with all the bad trouble that he went through. So I said no. (Carrie)

Health and welfare decision-making was therefore generally managed by these intellectually disabled people by having a supporter with them at healthcare appointments. Lasting Power of Attorney was also used in positive ways by these participants as a decision-making support tool.

LEGAL

Our research found very low levels of awareness and/or willingness to engage with decisions on wills, power of attorney and advance decisions among care professionals. With respect to the latter, several care professionals voiced concerns over DNR orders issued without consultation with the patient or their family and over how far advance decisions would go in replacing treatment and rehabilitation opportunities.

Nora (55-64, Brain Injury Case Manager) shared an example of a supported end of life care plan of a person she has been working with for almost 20 years and more recently diagnosed with advanced vascular dementia. "Finding the hooks" by linking his condition to what was going on in the media, the case manager started the process with gentle conversations, and over a period of two months the pair went step by step through specific decisions about tube feeding, cardiopulmonary resuscitation etc. The plan was later signed off with the client, his lawyer and the community matron based on his preference, and is revisited every three to six months to identify any changes in his choices about his end of life care.

Financial Power of Attorney was discussed by several of the intellectually disabled participants. Reasons for granting power of attorney varied by participant, but most often, the catalyst for securing financial power of attorney came as a result of advice from, or interactions with financial services providers.

Alex was happy for his mother to have financial Power of Attorney to help him with budgeting, as he struggles with impulse control and said that he would waste his money without help. Yet the catalyst here was a difficult interaction with bank staff, which caused unnecessary delay in the replacement of Alex's debit card.

My dog chewed up my credit card. And [my mum] went in for me on my behalf because she's the joint account holder and they wouldn't let her do it [order a new card]. And they suggested in there that, [the Bank] suggested that she should become a power of attorney. So she applied through the court and it happened when my Nan was poorly and everything and she got it. And she went in there the other week and they said to her that she couldn't do it even though she had power of attorney, because she has to let the bank know. So I went down with her and I didn't have a rant, but it was close to it. I said, "look, there's a piece of paper here from the courts, stick to it, because" I said, "you're making me make decisions about

financial, I only wanted to come in to get my debit card replaced.” And so last week I finally got a debit card after three months. It’s hard when you’re having to go out, and you know you’ve got your card in your wallet but you can’t use it because the dog’s chewed the chip and everything. (Alex)

None of these intellectually disabled participants discussed having a will. Rebecca, whose mother had recently died, thought that she would like to make a will, but wanted to discuss it with her friend before taking action on it, thereby taking advantage of informal support systems.

RELATIONSHIPS AND FRIENDSHIPS

Care professional participants emphasized the importance of having a supportive family and social network in disabled people’s lives and they were most likely to offer them support to spend time with family and friends. Yet one of the areas care professional participants found very difficult to deal with was conflicts with families, especially when family members tried to override a disabled person’s wishes and preferences. Cases of abuse by family members, which sometimes went unresolved, were also reported by some participants and will be explored in future publications.

Our research also found that the areas of intimate relationships and sexuality are usually avoided by care professional participants in their interactions with disabled people unless concerns over abuse arise. Jenny (35-44, Neurological Rehabilitation Case Manager) called the area a “minefield” that they try to stay as far out of as they can, and “We try to support it in a way that means we’re keeping them safe.” Patricia identified this reluctance among her colleagues:

We talk about holistical needs, and I’m very passionate about this, but we never touch upon the person’s sexuality or sexual needs. And I know it’s a private matter but why don’t we broach it if we’re talking about holistical needs? We talk about their education, we talk about their employment, we talk about their physicalness, but we never talk about sexual needs. So I’ve started to actually, in my working practice, to slowly skirt around that and just by saying to them, you know, pre-accident, did you have relationships, what do you feel about them now, would you like to, and I’ve touched upon those issues and touched upon whether they want relationships. And I’ve found out quite a lot, some of them, do want relationships, but because nobody talks about it, they don’t talk about it. (Patricia, 35-44, Senior Case Manager)

Another brain injury case manager, Nora (55-64) told of the work she did to address a disabled person’s sexual needs after the person endangered himself trying to go to a brothel. After this incident, Nora got into contact with a collective of sex workers and a sexual health service for disabled people, and developed a support plan to facilitate his access to sex workers. Nora constructed this plan also as part of a larger skills building program to gradually forge personal and romantic relationships. Facilitating access to sex workers for disabled people is a complex issue that needs to be considered very carefully due the challenging criminal law issues that are involved.

Given the importance of sexual expression and relational lives, and the challenges faced by some care professionals in trying to support their service users to develop safe relational interactions, these findings suggest that some more nuanced thought may need to be given to the legal and social complexities of supported decision-making about relational choices. Legal and social barriers preventing care professionals from supporting disabled people’s sexual expression should be

addressed and more holistic understandings of support may need to be developed to enable disabled people to achieve meaningful, fulfilling and enabling relationships.

In contrast to the relative absence of consideration of intimate relationships from care professionals, and the challenges the criminal law poses to care professionals working to support the development of relationships, several of the intellectually disabled participants described being in current intimate relationships. Four were engaged, and a further four spoke of their boyfriend or girlfriend. Two further participants were divorced. All of the intellectually disabled participants spoke about friendships beyond their family networks.

Michelle, for example, spoke about her boyfriend, who she had been in a relationship with for around four years. They met at a disability sports day:

We were in a wheelchair race and he actually fell out of his wheelchair. He's got a tendency to fall out of his wheelchair. And he's very naughty, he won't wear footplates or seat belt. I went and asked him if he was alright. And then after that day we had a BBQ and disco. That's where we were dancing all night, and we exchanged, he actually asked my carer if he could take me home because the taxi broke down that night. It broke down on the way to pick me up. So that's how I was waiting in the foyer with [him]. I actually lost the number, the carer kept it in her purse luckily. (Michelle)

Whereas Michelle lives independently (with support from her Personal Assistant and care team), her boyfriend lives at home with his family, and doesn't have the same level of care and support in place. They have been on holiday together, but because he doesn't have a care team, they are quite constrained about where they can go. In the past, Michelle has been on holiday to Spain with her care team, but when she goes away with her boyfriend they have to stay in the UK.

Well, this is the thing: I want to go to Spain, but then I want to be with my boyfriend, which means I have to go in England, which is, I think my boyfriend could make more decisions for himself but his mother doesn't seem to think so. But she's a lovely lady. (Michelle)

The stories told by participants about their relationships suggested that engagement with community services, in particular those specifically aimed at disabled people, was a good way of meeting friends, and potentially developing intimate relationships. Michelle met her boyfriend at a sports day; Carrie met her boyfriend at college; Colin met his girlfriend at a day centre. These kinds of activities are therefore crucial in not only supporting life choices, but also in facilitating peer networks, friendships and potential relationships.

SUPPORTED DECISION-MAKING - RECOMMENDATIONS:

- 7. Nuanced support and communication approaches, building on strategies developed for everyday and life choices, should be utilised for more complex life choices and legal decisions.**
- 8. More research is needed into how banks and financial institutions engage with customers with intellectual disabilities, effective support frameworks for everyday financial management, and managing bills and payments.**
- 9. More research is needed into how the MCA is used in medical consent processes for people with intellectual disabilities.**
- 10. Given the importance of future planning, further research is required into how best to support people with intellectual disabilities in making wills, advance decisions and granting Power of Attorney.**
- 11. A shift in social attitudes about intellectually disabled people, relationships and friendships is required to better support the relational lives of people with intellectual disabilities, particularly those living in care homes and supported living environments.**

6: GOVERNANCE, REGULATION AND POLICY

The final part of this report focuses on the interaction of everyday decisions with regulatory and policy dimensions of social care practice. We focus here on state support and welfare benefits, advocacy, care planning, and the relationship between supported decision-making and capacity assessments under the MCA.

STATE SUPPORT AND WELFARE BENEFITS

The detrimental impact of cuts to state support and reforms of the welfare benefits system since 2008/09 was highlighted by the Committee on the Rights of Persons with Disabilities in their Concluding Observations on the UK.^{vii} They were particularly concerned about the detrimental impact on people with disabilities related to Universal Credit, the sanctions regime associated with Employment and Support Allowance (ESA) and the reduction in disability support as a whole as a result of the introduction of the Personal Independence Payment (PIP). At the time of these interviews, none of the participants were in receipt of Universal Credit, but several had experienced problems associated with ESA and PIP.

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 [name], 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 organisations 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 organisations 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 £1,000 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)

Even leaving aside the human rights infringements identified by the Committee on the Rights of Persons with Disabilities, 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 state benefits system. These tales, alongside others, such as Tracy’s story about the difficulties of finding appropriate housing because of the ‘bedroom tax’ implications that we reported in Chapter 5, bring in to sharp focus the ways that the essentially punitive nature of contemporary welfare support frameworks exacerbate challenges experienced by intellectually disabled people.

ADVOCACY

Intellectually disabled people have a right to an Independent Mental Capacity Advocate under the MCA^{viii} when a person has no appropriate family member or friend available to be consulted, and they are considered to lack capacity to make a decision about a long-term change in accommodation or serious medical treatment. There are also potentially wider rights to advocacy under the Care Act 2014,^{ix} where care and support needs are being assessed or decided upon by local authorities.

Advocacy was seen by care professionals as an important element of supporting people with disabilities, particularly where their views were different from, or in conflict with, those of their families. Care professionals tended to report utilising advocacy services when there was some form of conflictual decision to be made. Lucy, for example, told a story of drawing successfully on the services of an independent advocate when a service user expressed their desire to live independently, and to move away from her family.

Now we have to be careful with where we lie to be able to support the individual, and to support the family as well, and not be the middle person, in that kind of sense. I spoke to an advocacy agency and got someone involved to be able to speak to my service user, to be able to follow that decision and the opportunity to be able to live on her own. So in that sense where she was quite able - she’d got a mild learning disability, she had got some sort of capacity to understand - this person, the advocate was here to support her in what she wanted to do.

The advocate got involved and obviously made regular visits, built that friendship up. We needed to remain impartial from all that, the decision making, because although we were a support person if you like as a day centre, we wanted to remain a support for the family as

well, because that's who we are and that's what we do. So we didn't want to be directly involved in that, but we supported the individual to maintain the friendship with the advocate. We gave them time, we gave them space, we gave them opportunities to meet and we'd all support that. This service user then was identified living arrangement for them to go and live if you like. We supported in transition, so we gave the information to the staff identified to work in that area. We supported them to tea visits, do you know what I mean, so that that then was looked at. Unfortunately, a few months down the line, she left us as day care, because she went on to pursue other things. She wanted to look at voluntary work, and she'd found a new lease of life basically. (Lucy, 35-44, Care Manager)

A number of care professionals mentioned that getting an independent advocate for the people they are supporting has not always been easy. Julia (45-54, Care Manager) told about an accommodation decision where the local authority first did not instruct an IMCA despite the review being done under the Care Act 2014; Alice (55-64, Case Manager/Occupational Therapist) said "I know you're meant to have IMCAs, but trying to get an IMCA is a nightmare."

Independent advocacy services were not discussed by the intellectually disabled participants in this research. In contrast, disabled people's self-advocacy projects were considered to be extremely useful for making sure that the voices of disabled people were heard. Such projects also provided opportunities for intellectually disabled people to work, with support, for the benefit of themselves and their peers. Gareth, who had been heavily involved in the self-advocacy movement for several decades, explained the importance of self-advocacy as supporting disabled people to choose their support, and develop their skills.

I was always told in my life, when you went to a traditional day service you had to go by the rules, regulations. You couldn't do anything out of context if you know what I mean. You're always told what to do and you cannot do this, you cannot do that, and so forth. But when the opportunity of looking at having an organisation which people with learning difficulties can have for themselves, and choose their own support and develop their own skills and run it, it was a different meaning. (Gareth)

The period of 'austerity' in UK politics from 2009 onwards was very difficult for disabled people's self-advocacy organisations. Funding cuts put many services at risk, and funding remains precarious for some organisations, despite the clear benefits of supported self-advocacy groups for disabled people's skills development, peer networks and self-esteem. Throughout this research, we found that self-advocacy and community engagement were sources of positive support and empowerment for intellectually disabled people. Such services are vital mechanisms to support independent living, and legal capacity.

CARE PLANNING AND PAPERWORK

Care professionals often emphasized the central role of documents in their work. Care plans, in particular, were seen as a comprehensive guide covering important aspects of disabled people's

lives. Care planning facilitates care professionals' interactions with disabled people and enables them to track and document their characteristics, progress and changing needs over time. Through such documentation, information regarding support given to disabled individuals can also be shared more easily within and between different groups involved in their care, like their families, support workers, GP's and other professionals.

As much as care professionals rely on care plans, the limits of trying to put lived experience into writing were also highlighted.

I've always said to staff coming in, you can read the care plans and you know what it's a brilliant guideline to what you need to do. But you will not fully understand the client until you start working with them, see the behaviours, see the way they communicate and then you'll fully understand.

When you read the care plans and it says "oh this person, his communication skill is so limited." But when you actually watch that person on a day to day basis, and you watch his body language, you realise how [much] more communication skill that person is displaying, even though they can't verbalise what they're saying through communication, their body language says a lot. (Jennifer, 35-44, Team Leader)

Documentation through care plans or other written tools was an important mechanism for care professionals to protect disabled people's rights as well as themselves by showing why and how a particular decision has been made or action carried out. While Nicole (55-64, Senior Care and Support Worker) put the need for documentation "so that we're not abusing the power that we have got here", Eva (35-44, Care Co-ordinator) framed it as "protecting yourself as well as the people you're looking after."

Several care professionals mentioned the increasing amount of paperwork they have to do and some felt that it takes them away from spending time with people that they came into the profession for. Julia (45-54), a care manager said: "There's no point me trying to write care plans and all this if I actually don't know what the lads' needs are and how they need things done and what they need to do, so otherwise it is just a paper exercise."

The way that paperwork gets in the way of doing care, especially when it becomes as an aim rather than a tool to provide good quality care was also voiced by Julia:

More and more time is spent, because everything now it's paperwork and paperwork, and you've got to prove you're doing stuff, rather than the actual doing it, it doesn't seem to matter so much anymore, as long as you've got a piece of paper to say this is what you've done. A lot of the agencies think that's far better than actually doing the job. ... Whether we actually do it or not doesn't seem to make much difference. (Julia, 45-54, Care Manager)

The task for regulators, policy makers and care professionals is to balance the different aims and objectives of paperwork and care planning to facilitate excellent care and support, whilst also empowering people with intellectual disabilities to make their own decisions. Legal and policy recommendations for change must, therefore, balance the needs for accurate and meaningful record-keeping with the primary focus of care and support. Sufficient time needs to be built in to care professionals' working hours to support care planning and record-keeping, without detracting from hands-on care. Achieving the right balance is likely to require additional investment in frontline care professional time.

SUPPORTED DECISION-MAKING AND CAPACITY ASSESSMENTS

The Mental Capacity Act operates in practice through capacity assessments. Whilst the legislation formally requires “all practicable steps” to be taken to assist a person to make their own decision before they are found to lack capacity,^x the lack of specific legislative provisions for supported decision-making within the MCA appeared to mean that this step may be missed out in formal capacity assessment contexts.

And you know I'm well aware in theory that the act says you shouldn't consider someone incapacitous until all practical steps have been taken to help them achieve capacity. And I never know what that means. I really don't know what that means and I don't know what all means and I'm never quite sure what practical means. But I do know that I am increasingly reminding myself that you can be capacitous with support and I should look very carefully at what support is available. (Andrew, 65-74, Mental Capacity Assessor)

The MCA Code of Practice makes very clear that supported decision-making is a necessity under the MCA. Yet some of the participants in this research who regularly assess mental capacity under the MCA for the Court of Protection, were either unclear about what supported decision-making involves, or were reluctant to use supported decision-making on an ongoing basis.

In our hospital we had a lady who was, her memory was shot to bits. She had a disease based illness. She could make lots of decisions. She could say exactly what she wanted. But she had absolutely no, she had appalling memory and she couldn't weigh things up. Anyhow there was an ongoing debate about her capacity. And we had various views and everybody except one head of service, then head of psychology, thought she lacked capacity. And we had a final meeting before it all fell apart, with the doctor and this that and the other and we looked at her. And the person with the alternative opinion said this lady doesn't lack capacity so long as she's supported all the time in all her decisions. And I thought that's absolute rubbish. I mean how can you do that? How can you provide? (Linda, 65-74, Mental Capacity Assessor)

These questions, of how far the MCA goes in supporting decision-making by people with intellectual disabilities goes to the heart of this research. We found that whereas supported decision-making

approaches were well embedded in front-line care practice in relation to everyday care and welfare matters, they were less commonly used in relation to major life choices or difficult decisions. Many of these care professionals did, however, see the value of supported decision-making even where, without support, their client or service user would be considered to lack capacity.

We scaffold people. So often when I support someone, I'm scaffolding. So actually a lot of people I work with probably lack capacity around a lot of decisions, but we support them, so you support that decision making. So we're not going to end up down some capacity process and best interests and all of the costs and time, and that sense of disempowerment that someone might get in the middle of all that. Wherever possible we avoid it by supporting a decision that somebody's sees is in their best interests. (Adrian, 45-54, Brain Injury Case Manager)

One of the reasons why the application of the MCA functional test will often find that a person lacks capacity is that the approach to decision-making in the MCA is grounded in rational cognition. Decision-making in everyday life generally follows a person's likes and dislikes, operates within constraints, and is shaped by relational contexts. It often involves emotional and even irrational elements. Yet the MCA requires people with intellectual disabilities to make decisions in a highly formalised, and cognitively focused manner.

The Mental Capacity Act assumes that decision-making is cognitive, doesn't it? If you think about it, and yet I'm sure you make decisions emotionally. I certainly make decisions emotionally which are nothing to do with using and weighing. (Andrew, 65-74, Mental Capacity Assessor)

Some professional mental capacity assessors who use the MCA in their daily practice, suggested that the functional test for decision-making capacity under the MCA is difficult to use in practice. Other tests, like the ACE-III^{xi} are used by (clinically trained) mental capacity assessors in its place. Whilst it is to be expected that professional psychologists and psychiatrists will use tools such as these, that have been developed for practical and professional application, the relationship between these cognitive screening tests and the functional test of capacity under the MCA is not at all clear. The ACE-III, for example is an abstract test of cognitive ability, requiring the person being tested to perform a number of standardised tests. These include cognitive activities like repeatedly subtracting 7 from 100, remembering three words for a period of time, linguistic reasoning and visuospatial abilities. The MCA, on the other hand, does not require disabled people to have these skills in order to make a decision with support.

The ACE-III is quick and it's very, it's very accurate. So it's very helpful if I have no idea about how someone is functioning cognitively. So I will quite often do that. If there is documentary information available, particularly about day-to-day decision making I want to see that. Sometimes there is, sometimes there isn't. You know there might be support worker notes for instance, there might be carer documents and that can be very helpful. If it's a question of does this person have capacity to litigate? I will quite often say to the solicitor, are you happy to accept instructions from this person and if they say well don't be stupid, that's why I'm asking you for a capacity assessment that tells me immediately that they're not at all happy about capacity. So this is the issue of capacity. So face-to-face interview, sometimes cognitive assessment, scrutiny of documents depending what's available. (Andrew, 65-74, Mental Capacity Assessor)

Several professionals noted disagreements about whether or not a particular client or service user had capacity to make particular decisions. Sometimes, when people were considered to have capacity, this was used as justification for allowing them to 'walk away' from important support services, or to endanger their health or welfare. Care professionals also reported disagreements about capacity that underestimated a person's abilities to express their decisions. Eva's story about a young woman with cerebral palsy making her own will, having previously had very limited communication skills is particularly interesting in this regard.

There's a client that I work with now who's just made her will. But that was all done through the deputy. So they arranged for her capacity assessment. She's an interesting case actually. She was born with cerebral palsy. She's got really limited speech, like two or three words she could say. She's lived in the family home all her life, and they've got care staff. And recently she got a new therapist, a speech and language therapist who's given her an eyegaze. So they've given her an eyegaze and they've been working with her on how to use that. And over the last two years she's gone from somebody that didn't have any kind of input into what happened to her, to somebody that's just gone and made their own will.

Because with the therapist's help and the right technology she's actually been able to express an opinion, and it's been clear to everybody that she's a really intelligent young lady. The trouble is that her mum doesn't think that she has got all this ability. She doesn't think the therapist and her staff know her daughter as well as she does. And yet they're putting things in, they're helping her express these opinions when actually they're not hers. So mum is being very resistant and not letting her make her own decisions, and the staff are really stuck in the middle. (Eva, 35-44, Care Co-ordinator)

Finally, some participants noted the differences between the MCA and other common law tests of capacity, like the *Banks v Goodfellow* test for testamentary capacity. Where these differences were noted, it appeared that assessors found the specificity of the testamentary capacity test to be more useful than the abstract reasoning of the MCA.

The relationship between supported decision-making and capacity assessments under the MCA is at the very heart of this research. Some have suggested that the differences between the UN CRPD approach to decision-making and the Mental Capacity Act can be resolved with minor amendments of the place of 'wishes and preferences' within best interests decision-making.^{xii} In contrast, the lack of engagement with supported decision-making where capacity is assessed for legal purposes suggests that more extensive legal and social reform may be needed to bring the MCA system formally into

line with the UN Convention on the Rights of Persons with Disabilities. A first step would be to revise the Code of Practice to take account of the wealth of experience in supporting decision-making and assessing capacity that has built up over the decade since the MCA came into force. Further research is needed into how capacity assessments operate in different practical domains, with a view to understanding the effects of implementing the Committee on the Rights of Persons with Disabilities view that all forms of substituted decision-making should be abolished.

REGULATION & POLICY - RECOMMENDATIONS:

12. Policy makers should give serious thought to simplifying the benefits and sanctions regime in order to better support people with intellectual disabilities to an adequate standard of living and to access their communities.

13. Disabled people's self-advocacy organisations should be funded and supported to provide additional sources of advocacy, support and empowerment for intellectually disabled people that reaches beyond the statutory minimum requirements under the MCA and Care Act 2014.

14. Frontline care professionals must be given time to complete paperwork that does not detract from their practical care giving. Local and central government investment in care services should recognise the need for both high quality care-giving and care planning.

15. The Code of Practice on the Mental Capacity Act 2005 should be revised to take account of developments in practical approaches to supported decision-making and capacity assessment.

^{vii} Committee on the Rights of Persons with Disabilities 'Concluding Observations on the initial report of the United Kingdom of Great Britain and Northern Ireland' CRPD/C/GBR/CO/1, 3 October 2017. Available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>

^{viii} Mental Capacity Act 2005, sections 35-41, and Mental Capacity Act Code of Practice, Chapter 10.

^{ix} Care Act 2017, section 67-68, and The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014 SI2014/2889.

^x Mental Capacity Act 2005, s. 1(3)

^{xi} Addenbrooke's Cognitive Examination, 3rd edition

^{xii} Law Commission *Mental Capacity and Deprivation of Liberty* (Law Com no 372, 2017); Martin et al (2014) 'Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales compatible with the UN Convention on the Rights of Persons with Disabilities? If not, what next?' available at: <https://autonomy.essex.ac.uk/wp-content/uploads/2017/01/EAP-Position-Paper-FINAL.pdf>

NOTES:

