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DOI:

[10.1111/jols.12331](https://doi.org/10.1111/jols.12331)

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Document Version

Publisher's PDF, also known as Version of record

Citation for published version (Harvard):

Harding, R 2022, 'Doing research with intellectually disabled participants: reflections on the challenges of capacity and consent in socio-legal research', *Journal of Law and Society*, vol. 48, no. S1, pp. S28-S43. <https://doi.org/10.1111/jols.12331>

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Doing research with intellectually disabled participants: reflections on the challenges of capacity and consent in socio-legal research

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Abstract

In this article, I reflect on the praxis of doing qualitative interview research involving intellectually disabled people as participants. I explore the ways in which ethical and legal norms work together to shape what is possible in research with intellectually disabled participants. I use stories from the field to explore issues of recruitment and sampling, working with ‘gatekeeper’ organizations, accessible information and informed consent, and data sharing and open access. As these reflections demonstrate, undertaking fieldwork involving intellectually disabled participants presents multiple challenges for socio-legal researchers. They also show that many of the challenges are surmountable, offering concerns, considerations, and solutions that can, and perhaps should, be considered by all socio-legal researchers who wish to ensure that all of the voices of society are included and reflected in their research.

1 | INTRODUCTION

In this article, I reflect on the legal, ethical, and practical challenges that arise when doing socio-legal research where some of the research participants are intellectually disabled people. I use the term ‘intellectually disabled people’ in a deliberately open and expansive way, including people with a range of cognitive impairments, such as learning difficulties/disabilities, autism, acquired

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brain injury, dementia, and other longstanding acquired or developmental cognitive impairments. Some of the arguments and issues that I raise here also apply to people with psychosocial disabilities.¹ Language in this area is, however, highly contested; different words and phrases are used in different countries, and by different groups, to refer to disabled people.² My approach to disability scholarship is founded in a political orientation towards the social model of disability,³ where the disadvantages and injustices experienced by disabled people are understood to be caused by society and social exclusion, rather than by disabled people's impairments. In using the term 'intellectually disabled people', I am seeking to highlight the ways that neurodiversity and cognitive impairments are stigmatized and devalued by social and legal norms and practices that prioritize or privilege neurotypical and non-disabled people.⁴

Despite the orientation of a great deal of socio-legal scholarship towards marginalized communities, relatively little empirical socio-legal research has been conducted that directly involves people with learning disabilities, dementia, or other cognitive impairments as research participants. There has been some observational research conducted in the Court of Protection,⁵ but much of that work focuses on the operation of the court rather than on the people whose lives are determined there, as disabled people often do not attend Court of Protection hearings about their lives.⁶ There are several intersecting reasons for this research gap, including legal limits on research participation by intellectually disabled people, ethical difficulties associated with conducting empirical research with 'vulnerable' participants, and practical challenges associated with recruitment and informed consent. As a result, significant knowledge gaps exist in socio-legal research about how intellectually disabled people experience law, and how regulation impacts on their life experiences.

Here, I reflect on my experience of undertaking the Everyday Decisions project.⁷ Reflective approaches to law and legality have also been used to articulate minority experiences within socio-legal studies,⁸ as well as to explore the subjectivity and positionality of the researcher.⁹ Reflecting on the experience of undertaking socio-legal research can also be a useful way of learning from the experience of others and sharing the messy realities of the research field,¹⁰ for which there is

¹ The Committee on the Rights of Persons with Disabilities uses the term 'psychosocial disabilities' to describe people with experience of mental ill health.

² R. W. Mackelprang, 'Disability Controversies: Past, Present, and Future' (2010) 9 *J. of Social Work in Disability & Rehabilitation* 87.

³ B. Clough, "'People like That": Realising the Social Model in Mental Capacity Jurisprudence' (2014) 23 *Medical Law Rev.* 53; T. Shakespeare, *Disability Rights and Wrongs Revisited* (2013, 2nd edn).

⁴ As a non-disabled, neurotypical researcher, I recognize, and am attentive to, the 'powerful' position that I inhabit.

⁵ L. Series et al., *The Participation of P in Welfare Cases in the Court of Protection* (2017); J. Lindsey, 'Developing Vulnerability: A Situational Response to the Abuse of Women with Mental Disabilities' (2016) 24 *Feminist Legal Studies* 295; J. Lindsey, 'Protecting and Empowering Vulnerable Adults: Mental Capacity Law in Practice' (2018) PhD thesis, University of Birmingham.

⁶ J. Lindsey, 'Testimonial Injustice and Vulnerability: A Qualitative Analysis of Participation in the Court of Protection' (2018) 28 *Social & Legal Studies* 450.

⁷ 'Everyday Decisions: Interrogating the Interface between Mental Capacity and Legal Capacity' funded by British Academy Mid-Career Fellowship (MCF150026); ESRC Impact Acceleration Account @UoB 'Supported Will-Making' (2017); ESRC Impact Acceleration Account @ UoB 'CLARiTY: Capacity Law and Rights Information to You'; further research also supported by a Philip Leverhulme Prize from the Leverhulme Trust.

⁸ See for example P. J. Williams, *The Alchemy of Race and Rights* (1992).

⁹ S. Subramani, 'Practising Reflexivity: Ethics, Methodology and Theory Construction' (2019) 12 *Methodological Innovations* 1.

¹⁰ S. Halliday and P. Schmidt, *Conducting Law and Society Research: Reflections on Methods and Practices* (2009).

rarely space in publications of research findings and arguments. My aim is to reflect on some of the legal, ethical, and practical issues that emerge when designing and undertaking research with intellectually disabled participants, and how I addressed these in my research. By sharing these reflections, I hope to encourage other socio-legal researchers to seek to include the voices of intellectually disabled people in their research, in order to ensure that their findings and arguments include these marginalized voices, experiences, and perspectives.

I begin with a brief introduction to the empirical research that gave rise to these reflections. I then outline the legal and ethical challenges posed by the regulatory framework for undertaking research involving people with impaired mental capacity in England and Wales. In the next section, through stories from the field, I reflect on my experience of doing research with intellectually disabled participants. I share my experiences of working with research ‘gatekeepers’ to recruit participants, the challenges of assessing capacity to consent to participate in research, and issues raised by moves towards open research and data sharing. I conclude with some reflections on the methodological implications of operationalizing a commitment to the social model of disability, and disability social justice, in empirical socio-legal studies.

2 | THE EVERYDAY DECISIONS RESEARCH PROJECT

The Everyday Decisions project explored how people with intellectual disabilities make decisions in and about their lives, and how care professionals support them in doing so. The research investigated how mental capacity law works in practice, with the aim of identifying areas of good practice, and areas where social change, practical interventions, or legal reform are required to secure disability social justice and protect human rights. The main legal focus of the project was on the operation of the Mental Capacity Act 2005 (MCA) alongside the right to enjoy legal capacity, set out in Article 12 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). The project was designed in the vein of legal consciousness research,¹¹ focusing on everyday experiences, rather than on access to justice or engagement with formal legal structures such as the criminal justice system or the courts. This qualitative research project included interviews with 15 disabled people, who were helped to participate by six supporters (some of whom supported multiple participants), and 25 care professionals who worked with people with intellectual disabilities.¹² A follow-up study, specifically focused on experiences of and attitudes to will making, included interviews with six disabled people, two of whom had also participated in the original study. In total, the project included interviews with 50 individuals, though my focus here is on the 19 disabled participants. Demographic information about these 19 participants is available in Table 1. Interviews with disabled participants took place in a space of the interviewee’s choosing. Many of these were in rooms adjacent to disability charity activities (n = 11) or in day centres (n = 4); a minority of interviews (n = 4) took place in the disabled participants’ own homes. Lone researcher protocols were followed to ensure researcher safety in private homes.¹³

¹¹ P. Ewick and S. S. Silbey, *The Common Place of Law: Stories from Everyday Life* (1998); D. Cowan, ‘Legal Consciousness: Some Observations’ (2004) 67 *The Modern Law Rev.* 928; R. Harding, *Regulating Sexuality: Legal Consciousness in Lesbian and Gay Lives* (2011).

¹² For further information about the demographics of the participants, see R. Harding and E. Taşcıoğlu, *Everyday Decisions Project Report: Supporting Legal Capacity through Care, Support and Empowerment* (2017).

¹³ See for example Social Research Association, *A Code of Practice for the Safety of Social Researchers* (2001).

TABLE 1 Disabled participants in the Everyday Decisions project: demographic information

Age group		Gender	
18–24	5% (n = 1)	Male	37% (n = 7)
25–34	21% (n = 4)	Female	63% (n = 12)
35–44	21% (n = 4)	Impairment(s)	
45–54	21% (n = 4)	Learning difficulty	79% (n = 15)
55–64	21% (n = 4)	Sensory impairment	21% (n = 4)
65–74	11% (n = 2)	Physical impairment	47% (n = 9)
Living arrangements		Acquired brain injury	11% (n = 2)
With family	3	Autism	11% (n = 3)
Supported living	6	Supported at interview	
Independent	9	Supporter present	63% (n = 12)
Care home	1	No supporter	37% (n = 7)

Note: Totals do not add up to 100 per cent as several participants had multiple impairments.

Key findings from the project included that while the MCA and the principles that underpin it were well embedded in professional practice, few interviewees had heard of the UN CRPD. Despite this lack of professional awareness of disability human rights, we found that intellectually disabled people, including those with profound and multiple disabilities, were often facilitated to make choices about everyday activities, food, and clothing. For those with limited verbal communication, multisensory approaches were often used, including objects of reference, talking mats,¹⁴ and pictures of choices. Disabled participants reported being well supported to make decisions about their lives, including important life choices around education, employment, and living arrangements, though the latter were sometimes limited by factors outside their control. Paradoxically, participants reported that more complex decisions were often less well supported.¹⁵ Findings from the research, and the follow-up study on supported will making, have been published elsewhere.¹⁶

Undertaking research with intellectually disabled participants is particularly time consuming and challenging. While reaching and recruiting participants from marginalized communities is always a challenge for researchers, adding intellectual disability into that mix requires careful, attentive, relationship building with organizations that share your values and goals, as well as attentiveness to a complex set of legal restrictions and ethical issues.

¹⁴ For details about this communication tool, which uses symbols to aid communication, see <<https://www.talkingmats.com/about-talking-mats>>.

¹⁵ Harding and Taşcıoğlu, op. cit., n. 12.

¹⁶ Id.; R. Harding and E. Taşcıoğlu, 'Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity' (2018) 8 *Societies* 25; R. Harding and E. Taşcıoğlu, "'That's a Bit of a Minefield': Supported Decision-Making in Intellectually Disabled People's Intimate Lives' in *Research Handbook on Gender, Sexuality and Law*, eds C. Ashford and A. Maine (2019) 256; R. Harding et al., *Supported Will-Making: A Socio-Legal Study of Experiences, Values and Potential in Supporting Testamentary Capacity* (2019); R. Harding, "'He Got Down on One Knee': Intellectual Disability, Intimacy and Family Law' in *Disability, Care and Family Law*, eds B. Clough and J. Herring (2021) 156.

3 | CAPACITY AND RESEARCH PARTICIPATION: LEGAL AND ETHICAL CONCERNS

Ethical principles have become firmly embedded in social research practice, with statements of the principles of ethical research practice being issued and regularly updated by research funders and learned societies to guide academic research.¹⁷ Doing research with intellectually disabled participants raises additional legal and ethical challenges for researchers, over and above standard considerations, which need to be addressed from the design phase of a research project. In this section, I explore some of the regulatory dimensions of undertaking research involving intellectually disabled people in England and Wales arising from the MCA, practices and processes of assessing and supporting capacity to consent to participate in a research project, and the challenges of loss of capacity during the research process.

3.1 | The Mental Capacity Act 2005

While there are international ethical guidelines for research¹⁸ and transnational legislation governing clinical trials,¹⁹ law and regulation relating to participation in social research varies across jurisdictions.²⁰ The MCA governs decision making of all kinds by and for people with impaired mental capacity in England and Wales. It (only) applies to decisions made by and for people who lack capacity to make a specific decision ‘because of an impairment of, or disturbance in the functioning of, the mind or brain’.²¹ In addition to bringing a general framework for decision making by and for intellectually disabled people into English law, the MCA introduced legal restrictions on and rules for conducting research involving people who lack capacity to consent to participate in that research.²² These require ethical approval by an authorized body,²³ and engagement with a consultee. To gain approval from an authorized body, research must be ‘connected with’

¹⁷ See for example Socio-Legal Studies Association, *Statement of Principles of Ethical Research Practice* (2009), at <https://www.slsa.ac.uk/images/slsdownloads/ethicalstatement/slsa%20ethics%20statement%20_final_%5B1%5D.pdf>; Economic and Social Research Council, ‘Framework for Research Ethics’ *ESRC*, at <<https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/>>.

¹⁸ See for example Council for International Organizations of Medical Sciences (CIOMS) & World Health Organization (WHO), *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (2016); World Medical Association (WMA), *Declaration of Helsinki: Ethical Principles for Medical Research Involving Humans* (2013).

¹⁹ See for example Regulation (EU) 536/2014 of 16 April 2014 on Clinical Trials on Medicinal Products for Human Use and Repealing Directive 2001/20/EC [2014] OJ L158/1.

²⁰ There is not space here to provide a survey of different jurisdictional contexts for capacity and consent in social research, given this wide jurisdictional variation, and comparative research has not been published that summarizes the different legal schema worldwide. For a discussion of data sharing and consent across jurisdictions, see A. Thorogood et al., ‘Consent Recommendations for Research and International Data Sharing Involving Persons with Dementia’ (2018) 14 *Alzheimers & Dementia* 1334.

²¹ Mental Capacity Act 2005, s. 2.

²² *Id.*, ss 30–34.

²³ *Id.*, s. 30(4); Mental Capacity Act 2005 (Appropriate Body) (England) Regulations 2006, UKSI 2006/2810, as amended. Currently, in England, it is usually the Health Research Authority who are responsible for ethical review of research involving health or social care where participants may lack capacity.

an ‘impairing condition’ that affects the person, or its treatment.²⁴ People who lack capacity can only be included in research if the research objectives cannot be achieved without their inclusion.

These restrictions on research involving participants who lack capacity to consent were introduced because at common law non-consensual touching (including as part of a research project with ethical approval) could give rise to actionable legal harms, including battery, and proxy consent (sometimes required by ethics committees) had no legal meaning.²⁵ Instead of proxy consent, the MCA created a personal consultee system that requires third parties to provide researchers with advice about whether or not a person who lacks capacity should be included in a research project.²⁶ The MCA also requires the focus of the research to be on the impairing condition affecting the person or its treatment, which may create barriers to involving intellectually disabled people in research about issues that do not relate to health and social care.

Despite these restrictions on research involving intellectually disabled people, their experiences of, and perspectives on, law and regulation are extremely important for understanding how law works in their lives. Intellectually disabled people are one of the most marginalized groups in the United Kingdom (UK). In 2016, the report of an inquiry into the UK by the Committee on the Rights of Persons with Disabilities highlighted systematic violations of the rights of persons with disabilities connected to changes to the welfare system from 2010 onwards.²⁷ Disability hate crimes recorded by the police increased by 250 per cent in five years, from 3,393 in 2015 to 8,459 in 2020.²⁸ Finding legal and ethical ways to listen to the voices of intellectually disabled people in socio-legal research is, therefore, vital to understanding the nuances of these human rights violations, experiences of crime and abuse, and other experiences of law and (in)justice by disabled people.

3.2 | Assessing and supporting capacity to consent to participate in research

This regulatory complexity means that, despite the centrality of the presumption of capacity, university research ethics committees are often very concerned about how capacity to consent to participate will be assessed by researchers.

The MCA contains a single test for capacity: that the person understands the information relevant to the decision (including the reasonably foreseeable consequences of deciding one way or another or of not making the decision), retains that information for long enough to make the decision, uses or weighs the information when they are making the decision, and is able to communicate their decision.²⁹ Under Principle 2 of the MCA, the person must also be given all practicable

²⁴ Mental Capacity Act 2005, s. 31(2). By contrast, proxy consent is required for clinical trials. Medicines for Human Use (Clinical Trials) Regulations 2004 UKSI 2004/1031, as amended.

²⁵ Law Commission, *Mental Incapacity* (1995).

²⁶ Mental Capacity Act 2005, s. 32. Contrast this with the Adults with Incapacity (Scotland) Act 2000, s.51(3)(f), which provides for proxy consent on the basis of substituted judgment.

²⁷ Committee on the Rights of Persons with Disabilities, *Inquiry Concerning the United Kingdom of Great Britain and Northern Ireland Carried Out by the Committee under Article 6 of the Optional Protocol to the Convention* (2017) United Nations CRPD/C/15/4.

²⁸ Home Office, *Hate Crime: England and Wales 2019–20* (2020). It is important to note that at least some of this shocking increase will be due to higher levels of reporting.

²⁹ Mental Capacity Act 2005, s. 3.

support to make the decision before they are found to lack capacity.³⁰ Decision-specific tests for capacity to consent to or engage in many activities have been discussed at length in the Court of Protection,³¹ but capacity to consent to participate in research has not been the focus of judicial interpretation to date. Guidance for researchers is available in the MCA Code of Practice, and has been issued by various bodies, including the Health Research Authority³² and the General Medical Council,³³ as well as in research ethics frameworks from learned societies³⁴ and funders.³⁵ In clinical and diagnostic practice, various psychological tests are used to assess cognitive abilities.³⁶ These are not, however, appropriate for use in research as they are general tests of cognitive ability, rather than directed at the question of whether a potential participant has capacity to consent to take part in a particular research project. Instead, consent processes in research should use all available supports, and ensure that any capacity assessments are directed specifically at assessing understanding of the information relevant to participation in the research.³⁷

In the research context, the relevant information should be included in the participant information sheet. Wherever possible, that information should be made available to participants in a format that they can understand. In the Everyday Decisions research, which (in line with the MCA) excluded participants who lacked capacity to consent, we used two versions of the project information sheets and consent form for interviews with intellectually disabled people: a standard plain-language version and a version that used icons and pictures to help to explain the written language (Figure 1). This latter form of presenting information is called ‘easyread’ and can be a ‘reasonable adjustment’ under the Equality Act 2010. Icons, photographs, and line drawings can be used to support text in easyread documents.³⁸ In the Everyday Decisions project, we used icons for the participant information and consent forms. In retrospect, iconography can be overly abstract as a way of presenting information, and easyread documents work best when the images are more literal. Specially drawn images, such as those that we commissioned for use in the Everyday Decisions project easyread report, allow more of the textual information to be conveyed through the image.³⁹

³⁰ Id., s. 1(3).

³¹ See for example J. Lindsey and R. Harding, ‘Capabilities, Capacity and Consent: Sexual Intimacy in the Court of Protection’ (2021) 48 *J. of Law and Society* 60.

³² Health Research Authority, ‘Mental Capacity Act’ *Health Research Authority*, 12 October 2021, at <<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/mental-capacity-act>>.

³³ General Medical Council, *Good Practice in Research and Consent to Research* (2020), at <https://www.gmc-uk.org/-/media/documents/Good_practice_in_research_and_consent_to_research.pdf_58834843.pdf>.

³⁴ Socio-Legal Studies Association, op. cit., n. 17.

³⁵ Economic and Social Research Council, op. cit., n. 17.

³⁶ See for example M. F. Folstein et al., ‘“Mini-Mental State”: A Practical Method for Grading the Cognitive State of Patients for the Clinician’ (1975) 12 *J. of Psychiatric Research* 189; E. Law et al., ‘Does the Addenbrooke’s Cognitive Examination-Revised Add to the Mini-Mental State Examination in Established Alzheimer Disease? Results from a National Dementia Research Register’ (2013) 28 *International J. of Geriatric Psychiatry* 351; C. Zadikoff et al., ‘A Comparison of the Mini Mental State Exam to the Montreal Cognitive Assessment in Identifying Cognitive Deficits in Parkinson’s Disease’ (2008) 23 *Movement Disorders* 297.

³⁷ Thorogood et al., op. cit., n. 20.

³⁸ High-quality easyread image providers include CHANGE (<<https://www.changepeople.org>>) and Photosymbols (<<https://www.photosymbols.com>>).

³⁹ R. Harding and E. Taşcıoğlu, *The Everyday Decisions Research Project: Findings Summary* (easyread version) (2017), at <https://legalcapacity.org.uk/wp-content/uploads/2017/12/EverydayDecisionsFindings_EasyRead_Web.pdf>.



Interview Information

We want to talk about how you make decisions about living, working, money, friends and relationships:



Use this information to help you decide if you want to talk to us.

FIGURE 1 An excerpt from the Everyday Decisions project easyread participant information sheet

Since 2016, there has been an accessible information duty in relation to health and social care. This means that all health and social care providers have a legal responsibility to provide information in formats accessible to their patients or service users.⁴⁰ No equivalent legal duty arises for researchers or for other service providers. Yet the provision of accessible information is as crucial to inclusion for intellectually disabled people as physical alterations are for wheelchair users, and should be considered by all researchers. Increasing the accessibility of research information will widen the participant pool, allowing greater access to populations who are often thought of as ‘harder to reach’ for researchers. Most intellectually disabled participants in the Everyday Decisions project chose to use the easyread versions of the information sheet and consent form, though all were offered the choice, and some did not have learning difficulties (Table 1). Other participants could not read text, so, for them, the consent process was more iterative and process oriented.⁴¹ With those participants, I talked through the information in the participant information sheet, offering more explanation if needed, drawing on the intellectually disabled person’s chosen trusted support where appropriate, and answering any questions that the participant had to help them to understand the information relevant to consenting to participate in the research.

3.3 | Loss of capacity during a research project

Another consideration in conducting lawful research under the MCA is what to do if participants lose capacity to consent to continued participation during a research study. Much socio-legal research (including the Everyday Decisions project) is undertaken as ‘snapshot’ research, involving a single point of data collection. In many cases, this will mean that loss of capacity during the empirical phase of a research project is not a major problem, because capacity need only persist through the period of time covered by recruitment, consent, and undertaking the interview or

⁴⁰ NHS England, *DCB1605 Accessible Information: Specification v1.1* (2017). For further discussion, see Harding et al., op. cit., n. 16; I. Rafi et al., ‘The Accessible Information Standard: Action and Reaction’ (2016) 66 *Brit. J. of General Practice* 64.

⁴¹ J. Dewing, ‘Participatory Research: A Method for Process Consent with Persons Who Have Dementia’ (2007) 6 *Dementia* 11; M. Tolich, ‘Purpose Built Ethical Considerations for Narrative Research: Broad Consent or Process Consent but Not Informed Consent’ in *The Routledge International Handbook on Narrative and Life History*, eds I. Goodson et al. (2017) 593; K. Usher and D. Arthur, ‘Process Consent: A Model for Enhancing Informed Consent in Mental Health Nursing’ (1998) 27 *J. of Advanced Nursing* 692.

other data collection process. In longitudinal research, however, or research involving more than one data collection point (for example, life history research, participatory action research, and photovoice methods⁴²), the issue of fluctuating capacity and/or cognitive decline poses greater challenges. These kinds of methods may be particularly well suited to involving participants with impaired decision-making capacity, because they are often participant led, enable greater rapport to develop between the researcher and the participants, and can be empowering.⁴³

The MCA included transitional arrangements for loss of capacity during research projects that began before it came into force in October 2007,⁴⁴ but is silent on what should happen if participants lose capacity during a research project that began after that time. The original (2007) Code of Practice on the MCA did not provide much further detail on this, and this has created challenges for university research ethics committees and researchers ever since.⁴⁵ The MCA does not contain any provision for advance consent (whether to participate in research or in respect of any other decision), only advance refusals of treatment and advance statements of preferences.⁴⁶ The basic principles are that if a participant loses capacity during the course of a research project (an issue of particular importance for research involving intellectually disabled people with neurodegenerative diseases such as dementia), then the personal consultee system under the MCA must be used, if that participant is to continue in the project. This means that the vast majority of longitudinal or two-stage dementia research requires ethical approval from an appropriate body (such as the Health Research Authority), even if at the point of recruitment to the study all participants have capacity to consent to participate, unless the researcher plans to withdraw participants who lose capacity during the project. Even if the latter approach is taken, researchers need to pay close attention to what happens to data already collected if a participant loses capacity and is subsequently withdrawn from the study, and plan for this eventuality.

The issues discussed here are by no means the only legal and ethical challenges that arise in planning research with intellectually disabled participants, but they provide some of the key regulatory foundations that must guide research design and praxis in this area. Other important regulatory dimensions include the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. These have moved some aspects of research regulation away from prioritizing consent, by allowing for a range of exemptions relating to the processing of personal data for the purposes of research.⁴⁷ Informed consent does, however, remain important for common law duties of confidentiality.⁴⁸ Doing research with intellectually disabled participants also reminds us why careful attention to the ethical dimensions of research practice is so important. Standard ethical considerations, such as the importance of being particularly attentive to the needs of vulnerable

⁴² Photovoice methods use photographs taken and selected by participants to help them to reflect upon and explore their perceptions and emotions about things that concern them. See for example K. Budig et al., 'Photovoice and Empowerment: Evaluating the Transformative Potential of a Participatory Action Research Project' (2018) 18 *BMC Public Health* 432.

⁴³ Id.

⁴⁴ Mental Capacity Act 2005, s. 34.

⁴⁵ A revised version of the MCA Code of Practice is in development, which will provide updated information for researchers on this issue. There is also guidance on the Health Research Authority website. Health Research Authority, *op. cit.*, n. 32.

⁴⁶ Mental Capacity Act, ss 24–26.

⁴⁷ V. Chico, 'The Impact of the General Data Protection Regulation on Health Research' (2018) 128 *Brit. Medical Bull.* 109.

⁴⁸ Data Protection Act 2018; *id.*

subjects,⁴⁹ remain important in research with intellectually disabled people. The ethical principles of autonomy and informed consent provide the foundations of the MCA approach, but other ethical principles are similarly important.⁵⁰ By reflecting on accessible research practices that support the inclusion of intellectually disabled people, we can see how ethico-legal standards ensure high-quality research materials, consent processes, and practices. In the next section, I turn to explore how these ethico-legal foundations translate into research praxis.

4 | STORIES FROM THE FIELD

In this section, I share three stories from the field that help to bring to life some of the ethico-legal issues that shape socio-legal research with intellectually disabled people. Aspects of these stories have been changed, deliberately, to ensure and protect the anonymity of research participants. They are also told from my perspective, as a researcher, rather than from the perspective of participants. In these stories, I explore recruitment and sampling, gaining informed consent, and data sharing and giving feedback about the research to research participants. As these are reflective accounts, while they are separated into three neat tales, each of these reflections cuts across a number of facets of research praxis.

4.1 | Recruitment and sampling: engaging with ‘gatekeepers’

I have been doing and supervising research about issues relating to intellectual disability of one form or another for over a decade. In that time, I have built up relationships with a range of different charitable organizations, large and small, broad and narrow, working in the fields of care, dementia, and disability. I have drawn on some of these relationships to assist with recruitment to empirical research, with greater and lesser successes.

Some of the larger charities have created research governance processes to facilitate and streamline their assistance in recruitment. An example of this kind of framework is the Join Dementia Research portal funded by the Department of Health and Social Care, which offers researchers with ethical approval for their projects access to a large, research-ready participant group.⁵¹ Services like these can offer speedy recruitment of research-aware volunteers, but there are drawbacks to this kind of sanitized research recruitment approach. One challenge is that the same volunteers may be invited to be involved in a wide range of research studies, and may therefore become ‘expert’ participants, able to provide well-rehearsed stories. This may privilege some stories and experiences over others. Another challenge is that these databases of potential research participants are self-selecting, and so harder-to-reach participants (such as minorities within the group at the heart of the research) may remain difficult to recruit, therefore silencing their voices if researchers use a one-track strategy for recruitment through these means. Furthermore, some of these networks rely on online processes for recruitment, selection, and contact, which may limit

⁴⁹ D. Bracken-Roche et al., ‘The Concept of “Vulnerability” in Research Ethics: An In-Depth Analysis of Policies and Guidelines’ (2017) 15 *Health Research Policy and Systems* 8; B. G. Gordon, ‘Vulnerability in Research: Basic Ethical Concepts and General Approach to Review’ (2020) 20 *Ochsner J.* 34.

⁵⁰ T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics* (2013, 7th edn).

⁵¹ See <<https://www.joindementiaresearch.nihr.ac.uk/>>.

access to people with higher levels of education or income, or those of younger ages who are more confident in using online tools.

In many social science research projects with hard-to-reach groups, where there is little chance of recruiting a representative sample, non-probability 'snowball sampling' is used as an effective recruitment strategy.⁵² Snowball sampling is extremely useful as a convenience sampling mechanism for generating chains of participants from populations that are not clearly delineated, where the researcher has access to a primary informant from that population.⁵³ However, there are often challenges associated with snowball sampling that stem from the relative homogeneity of individuals' social groups, particularly alongside the selection bias that comes from self-selection to participate in research. When the researcher does not have strong links into the research population, then using 'gatekeeper' organizations as a way to locate participants can be helpful.

We took this gatekeeper approach to recruitment in the Everyday Decisions project. Recruitment to the project began with organizing a stakeholder meeting at the University of Birmingham and inviting a range of representatives from charities, local authorities, representative groups, and other interested parties. At this meeting, we carefully explained what the project was about, how it was funded, what our overarching research questions were, and how we hoped to answer them. We gave participants at that meeting the opportunity to ask questions and to put forward their own perspectives on priorities for the research. From that discussion, we were able to develop shared objectives with our stakeholders to take forward through the research project.

Not all of the stakeholders at that meeting were subsequently involved in the research. One local authority representative who attended was keen to support recruitment to the 'social care professionals' arm of the project, and asked us to complete their sponsorship form, accompanied by all of our ethical review materials, including recruitment materials, participant information sheets, consent forms, and evidence of ethical approval. The process of engaging with their research team took several months. While we did (eventually) receive governance approval, we did not successfully recruit participants through their local authority to either branch of the project. Other stakeholders, particularly those from smaller charitable and third-sector organizations that shared our understanding of disability social justice and the importance of disability human rights, were extremely helpful in opening doors for us into organizations they had worked with, helping us to recruit both social care professionals and intellectually disabled people from within their networks. After we had completed the empirical research and written up our findings, we returned to many of these gatekeeper organizations and presented our findings back to people in their networks who participated in their research. Intellectually disabled people who came along to presentations about the research expressed their agreement with the findings and were pleased to see the easyread version of the project report.⁵⁴

The use of gatekeepers as a mechanism for recruiting hard-to-reach populations as part of a snowball sampling strategy is an established way to access participants, but it can be challenging for all parties and it is important to be attentive to power dynamics within the relationship. While most of the relationships that we developed through the Everyday Decisions project were positive and long lasting, one organization stopped engaging with the research team after we had conducted interviews with some of their staff and service users. In part, this was a consequence of

⁵² M. S. Handcock and K. J. Gile, 'Comment: On the Concept of Snowball Sampling' (2011) 41 *Sociological Methodology* 367.

⁵³ R. Harding and E. Peel, 'Surveying Sexualities: Internet Research with Non-Heterosexuals' (2007) 17 *Feminism & Psychology* 277; Harding, op. cit., n. 11.

⁵⁴ Harding and Taşcıoğlu, op. cit., n. 39.

a misunderstanding about the use of video recording in interviews with disabled participants. A small video camera was used in these interviews as a way of recording body language and to assist with detailed transcription of the interviews. We used video because many people with intellectual disabilities communicate in complex ways, using a combination of speech, body language, and Makaton signs,⁵⁵ or may have impairments that affect the clarity of their speech. Participants were also encouraged to use pens and paper to help them to communicate, and any drawings were captured through the recording device.

In some research projects, video data or images of participants' drawings would be part of the dataset and used for analysis or presentation of findings. In contrast, in the Everyday Decisions project, despite acknowledging the value of that data for analytic purposes, the potentially vulnerable nature of the participants meant that we only sought consent for the research team to view the recordings, and not to use stills or clips from either the video or audio recordings of the interviews for any other purpose. When we approached this organization to help with the project, we gave the manager copies of all of the recruitment materials, including participant information sheets, which explained why we would like to video record the interview (if the participant consented to this), and the consent forms that allowed participants to consent to or refuse video recording of the conversation. We also had a conversation about how the interviews would work, including the use of audio and video recording equipment to enable the researcher to listen attentively to participants.

After several interviews had taken place, the manager contacted me with concerns about the use of video, claiming not to have known about it. I explained, again, the rationale, and that this was all detailed in the information sheets and consent forms that were shared with the organization, and all of the participants, before the research took place. This did appear to defuse what had rapidly become a fairly combative interaction, but the organization did not respond to our repeated invitations to share findings and recommendations from the research with staff and service users in person. As with many challenging interactions, I have replayed this series of events in my mind many times, as it was upsetting to be unable to close the research loop in the way in which I would have preferred. With the benefit of hindsight, I could have been more direct in my explanation of the use of video recording during the recruitment process, and this may have prevented the breakdown of the research relationship. We did, of course, send paper copies of the research reports to the organization, for the information of research participants and other staff and service users, but we did not hear back from them about their views on the findings. While the lack of response to the reports may well have been due to other pressures rather than to the video recording issue, this experience offers a salutary tale about the importance of clear communication with both gatekeepers and research participants.

4.2 | Assessing capacity and gaining consent in the real world

The process of carrying out the Everyday Decisions interviews with intellectually disabled participants is also worth reflecting on. As discussed above, the MCA creates a hard legal barrier to including intellectually disabled people who lack capacity to consent to participate in research that can be effectively conducted without their involvement. All of the intellectually disabled

⁵⁵ Makaton is a language programme that combines symbolic signs (similar to other sign languages) with spoken language as a way to develop and support communication. See further *Makaton*, 'What Is Makaton?' *Makaton*, at <https://makaton.org/TMC/About_Makaton/What_is_Makaton.aspx>.

participants in the research engaged with the participant information, whether independently through the written or easyread versions, with the assistance of their chosen supporter, or in conversation with the researcher. There was a separate participant information sheet and consent form for supporters. Despite this careful attention to participant information and consent, the translation of the rules in the MCA into practice in the field posed some challenges.

The consent process with one older male participant with learning disabilities is particularly memorable. This participant was incredibly keen to take part in the research. He was very quick to volunteer and really wanted to tell me about his life. He was not terribly interested in the participant information, and though he did read and engage with the written information, he did not ask any questions about it, and very quickly consented to all of the individual items on the consent form. This research participant had a supporter with him, who was not concerned about the speed with which he completed the consent process and did not raise any issues about his capacity to consent.

As a legal researcher, keen to ensure that I was working within the law, and within my ethical approvals, I felt the need to check his understanding of the information that he had been given. Despite the presumption of capacity, and his enthusiasm for participating in the research, I wanted to make sure that he had an appropriate level of understanding of what the research was about, and what I would do with what he told me. To do so, I asked him to translate into his own words various elements of the consent form. So, for example, I showed him the audio recorder and asked him if he knew what it was; he said yes. He was very interested in the video recorder (as were several of my research participants!) and in using it to record me when I showed him how it would work. As a result, for the vast majority of the consent form, I was reassured that he had understood the information relevant to his decision to take part, and that he had capacity to participate in the research. This experience suggests that it is important to design consent processes in ways that genuinely enable participants to consent to or refuse different aspects of participation, and that the MCA rules on capacity to consent may impact on participation at a relatively finely grained level within consent processes. In this participant's case, I was reassured by his ability to explain back to me the things to which he had consented. I remained, however, somewhat concerned about the depth of his understanding of the final point on the consent form, which asked for permission to archive anonymized transcripts in an open-access data repository.

4.3 | Data sharing

Open access to both research publications and research data is an increasingly important aspect of publicly funded research. Regulatory support, such as through open-access requirements for submission of research outputs to the UK's Research Excellence Framework, or international support for 'Plan S',⁵⁶ has facilitated rapid growth in open-access publishing. Open access to research data is rather more complex, as it requires data to be made available in shareable forms, while also being securely archived. As recognized by the UK Concordat on open research data, notwithstanding the potential benefits to research, it is not possible for all data to be open and 'access may need to be managed in order to maintain confidentiality, guard against unreasonable cost, protect individuals' privacy, respect consent terms, as well as managing security or other risks'.⁵⁷

⁵⁶ See <<https://www.coalition-s.org/>>.

⁵⁷ Higher Education Funding Council for England et al., *Concordat on Open Research Data* (2016).

The final question on the Everyday Decisions consent form sought permission to offer anonymized data from the project to a data archive, where it could potentially be used by other researchers in the future. While all participants could understand why I would want to keep data from the project, so that I could write up the findings and tell others about my participants' experiences, the concept of sharing anonymized data in an open-access archive was more difficult for me to explain and for many of my participants to comprehend. The idea of open research and data sharing is relatively new, and the juxtaposition of openness with the experiences of vulnerable research participants creates tensions. Research shows that many academics are uncomfortable in sharing data from their research, even where they understand the potential benefits for science and society in doing so,⁵⁸ and that different considerations apply in respect of qualitative interview data than quantitative data.⁵⁹ This is because qualitative data, especially qualitative interview data, is co-created within an interactional context between the researcher and their research participants.

In this research with intellectually disabled participants, I felt the relational nature of the research process, and the relationships of trust and power that are embedded in it, even more acutely than in other empirical work that I have done. While, for example, the work of conducting interviews with care professionals was shared between the research team,⁶⁰ I conducted all of the interviews with disabled participants personally. Having been a participant in these research conversations, reading the transcripts brings that interactional context fully to life for me: I can envisage the space where the interview took place, hear the background noises, recall the scents, and feel the sensations of being part of that conversation. As the interviewer, I know how many times I had spoken with each participant before the interview, and I can remember the kinds of questions that they asked about the research and about what would happen. I can remember how I built rapport, often by finding things in common between us (such as a shared interest in trains or a love of stationery). I noted some of these elements in contemporaneous fieldnotes, such as the background beep of a faulty smoke alarm or the way the smell of lunch being cooked in a day centre kitchen shaped conversations about food choices. The haptic sensations of these memories go further than any flat textual translation of an in-person interaction (no matter how detailed the transcription or fieldnotes are).

My sense was that ideas around, and the reasons for, sharing the transcript of their interviews were not well understood by many of these intellectually disabled participants. All of them had ticked or initialled their assent to data sharing on the consent form, and the consent form and participant information had been approved through ethical review, so the formalities of 'informed consent' had been adhered to. Yet I was not fully satisfied that their agreement represented genuine informed consent to their stories being accessed, used, and analysed by a potentially infinite number of unknown researchers in the future. This presented a dilemma for me, as a researcher, in navigating my legal responsibilities to conduct research only with participants who had capacity to consent to participate, and in relation to the expectations of the research funding body that data from the project would be made available through an open-access archive. In the end, I decided that the best course of action would be not to offer the data to an open-access archive. I

⁵⁸ B. Fecher et al., 'A Reputation Economy: How Individual Reward Considerations Trump Systemic Arguments for Open Access to Data' (2017) 3 *Palgrave Communications* 17051.

⁵⁹ A. Chauvette et al., 'Open Data in Qualitative Research' (2019) 18 *International J. of Qualitative Methods* 1609406918823863.

⁶⁰ Ezgi Taşcıoğlu worked with me as a research fellow on this project and conducted many of the care professional interviews.

had several reasons for this decision and, given the contemporary research governance emphasis on open access and data sharing, it was not an easy choice to make. I was concerned that much of the richness and depth of these participants' stories would be lost if these data were anonymized, as the nuance of body language could not be captured accurately in the transcripts, and my haptic memories of the interactions that are part of my understanding of these data would also be lost.

Issues around capturing body language and contextual information surrounding an interview transcript are equally applicable to any qualitative research data, particularly where it has been sanitized and anonymized for data sharing. We must, therefore, be attentive to what is missing when re-using previously collected data for secondary analysis. There are, of course, more detailed transcription protocols⁶¹ that can capture greater levels of nuance, and audio or video recordings could potentially be archived and shared with participant consent. In the context of vulnerable research participants or sensitive research topics, however, the importance of protecting participant privacy and confidentiality is likely to outweigh researchers' or research funders' desires to create a resource for secondary data analysis. Indeed, it is important to note the emphasis in the MCA that 'the interests of the person must be assumed to outweigh those of science and society'.⁶² While this technically applies in the MCA only to those who lack capacity to consent to take part in research, it is an important principle for researchers to bear in mind in conducting research with intellectually disabled participants.

5 | CONCLUSION

I have used reflexive methods to explore issues common to all empirical socio-legal research, while focusing in on the less usual context of undertaking interview research with intellectually disabled people. In reflecting on my experiences of doing this empirical work, and through my stories from the field, I have tried to bring new life to socio-legal considerations of ethical research praxis. Ethical review of research can, unfortunately, be viewed by some as an exercise in ticking boxes and jumping through regulatory hoops. In the context of the Everyday Decisions project, and in much of my research, I found that ethical review of research and engaging in ethical research praxis provided me with opportunities to consider the impacts of my research practices on participants, society, and social justice.

Doing empirical research with intellectually disabled participants presented me with a multiplicity of new challenges, posed by navigating a complex regulatory landscape, engaging in conversation with people whose life experiences are very different from my own, and developing a responsibility to make the case for their rights. Since doing this research, I have become increasingly passionate about the importance of accessible information in realizing disability social justice. Thinking carefully about how to include intellectually disabled participants in my research, how to ensure that I could support research volunteers to understand the information relevant to their participation, and how to close the research loop taught me a great deal about accessible communication and information.

Including intellectually disabled people in socio-legal research is essential to realizing disability social justice and human rights. Intellectually disabled people's lives are subject to a great deal of law and regulation – much more, often, than those of non-disabled people. In their everyday lives, disabled people have to navigate the MCA, the Deprivation of Liberty Safeguards, best-interests

⁶¹ G. Jefferson, 'Transcription Notation' in *Structures of Social Interaction*, eds J. Atkinson and J. Heritage (1984) 9.

⁶² Mental Capacity Act 2005, s. 33(3).

decisions, safeguarding, the Care Act 2014, access to advocacy, and the complexities of the benefits system. Unless we find ways to navigate the ethico-legal landscape that surrounds involving intellectually disabled people in research, we will continue to struggle to hear their voices. Without those voices, research about how law works in disabled people's lives will continue to be impoverished, creating and maintaining barriers to disability social justice. My hope is that these reflections will offer others a route map to help them to traverse the complex ethico-legal terrain of doing empirical socio-legal research with intellectually disabled people.

ACKNOWLEDGEMENTS

I would like to thank Linda Mulcahy, Rachel Cahill-O'Callaghan, and Anna Bryson for their comments on an earlier draft of this article. I am grateful to the British Academy, the Leverhulme Trust, and the ESRC IAA at the University of Birmingham for financial support for aspects of the research reported here.

How to cite this article: Harding R. Doing research with intellectually disabled participants: reflections on the challenges of capacity and consent in socio-legal research. *J Law Soc.* 2021;1-16. <https://doi.org/10.1111/jols.12331>