
Exploring the Implications of Disability Discrimination Law for Research Approval Procedures

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Abstract

This submission examines what modern Disability Discrimination Legislation may well mean for research approval procedures. The core feature of this legislation is that it creates sweeping, yet under-enforced, rights for people with disabilities in society. With the advent of the UN Convention on the Rights of People with Disabilities (UN CRPD), this includes the right for those with a wide range of disabilities to access and fully benefit from technology, and obligations to design research as to bring this about. This author proposes that research approval procedures require radical revisions in order to meet the obligations placed upon institutions. This includes appropriate support for researchers in sensitive settings, timely approval of research, and procedures that are actually designed to promote the inclusion of disabled subjects where appropriate.

Author Keywords

Disability Discrimination Law; Ethics; Research Approval Processes

Introduction

The underlying construct of disability discrimination law, *proportionality*, has two sides. Unfortunately, university

and institutional procedures for approving research tend to be designed with only one of these sides in mindⁱ. By this, I mean that research approval procedures are primarily intended to protect potential participants and the researchers themselves from actual harm. There is no 'other side' represented that considers whether disabled people need to be included in certain research, in order to ensure that their rights to equally benefit from it are fully taken account of.ⁱⁱ For the purposes of the human computer interaction community, this means that there is a reduced likelihood of systems being accessible to people with disabilities, and a reduced likelihood of people developing novel systems that address a particular population of people with disabilities.

Existing processes place strong administrative burdens on those who wish to investigate certain sensitive settings, and by implication, populations. Three years ago, a well renowned developmental psychiatrist documented the lengthy and unduly bureaucratic procedure, describing it as a "modern day circumlocution office".ⁱⁱⁱ Most troubling were the real implications for research into disabilities:

"The current system is deterring people from doing research. The problem is not with the individuals running the system: they've mostly been highly professional, helpful and competent, but they are running a modern Circumlocution Office. I've interacted with at least 27 people about my proposal, and that's not counting the Research Ethics Committee members. I'm a few years off retirement

and I've already decided that I won't tangle with NHS Ethics again. I'm in the fortunate position that I can do research studies that don't involve NHS patients, and I want to spend the time remaining to me engaged in the activity I like, rather than chasing pieces of paper so that someone somewhere can file them, or waiting for someone to agree that an innocuous letter from a Consultant to a GP is ethically acceptable."

That article was accompanied by a large number of concurring comments which made very similar points, and echoed the negative impact this had upon the choice of participants in research projects. Indeed, it accords with this authors own experiences of internal institutional procedures. On one occasion, I received ethical approval of a project – after several months – the day before I was about to fly out to perform recruitment (and potentially actual participant interviews). No reasons were provided as to why it was approved, or why it took more than two months to reach a decision, and it is impossible to find out who actually reviewed it, or to determine whether or not those people were qualified to do so. Nevertheless, I am fairly sure that they were not experts in the topic at hand; my current institution (amongst many others) has a policy of getting non-experts to review research proposals from an 'ethical approval' perspective, in order to avoid potential conflicts of interest. Performing a review of procedures at other institutions suggests similar problems and concerns, at least within the United Kingdom.

Box 1: Article 4 Extract of UN CRPD. (My emphasis in Bold)

*"States Parties undertake: To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes; ... To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise; **To undertake or promote research and development of universally designed goods, services, equipment and facilities**, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines; ...To **undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost**; ...To promote the **training of professionals and staff working with persons with disabilities** in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights."*

There are two problems that this article considers, arising from the present systems that serve as research approval processes. The first is obvious from the above discussion: research approval procedures often involve the completion of a large amount of bureaucracy of dubious necessity, and this in turn may well be having the effect of diminishing the research that is conducted, especially into certain disabilities. The second, and less obvious point is this: researchers conducting potentially sensitive research are not actually receiving adequate evaluation of their projects, providing a further deterrent towards this kind of work, and potentially failing to safeguard to the rights of participants.

I introduce disability discrimination law as it provides a framework for considering what an ethical research approval procedure should look like, from both the perspective of protecting the rights of individuals who may not be able to consent to research, as well as preserving the right of those with disabilities. This submission summarizes core parts of this legislation and uses it to indicate the kinds of steps that institutions should take going forwards in order to ensure that this legislation's impetuses are met. In doing so, it is hoped that this submission will be an effective tool for those who wish to bring about change within their own organizations, and perhaps beyond them.

Disability Discrimination Law

Below I set out some key provisions from disability discrimination law. The first addresses the UN CRPD, whilst the second explores its concrete implementation in UK legislation in order to provide an understanding of how these tools work in practice.

The UN Convention on the Rights of Persons with Disabilities (UN CRPD)

Initiated by Mexico in 2006, this convention^{iv} has now been ratified by the majority of world states, and other

countries are in the process of achieving ratification. Building upon the recent introduction of Disability Discrimination Law (e.g. through the US ADA 1990, or the UK Disability Discrimination Act (1995)), the stated achievement and outcome is as follows:

It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

This is in line with the social model of disability. Unusually for an instrument from the United Nations there are obligations in relation to technology, provided within Article 4 (**Box 1**). As can be seen, these are sweeping obligations, requiring state parties to promote or conduct research that ensures people with disabilities are fully included in society. There is a particular emphasis upon technology here, as well as practices. Another noteworthy obligation is to provide appropriate training to those working with disabilities. Both of these points would apply to research, and the design of approval procedures and support mechanisms.

The other key aspect of the convention is Article 12, which protects those who may have limited mental capacity, provided in **Box 2**. Amongst other things, this Article is concerned with protecting the rights of those with disabilities who cannot necessarily consent to research in a reliable fashion. It strongly emphasizes the need to balance the necessary safeguards with the liberties, freedoms, and other rights of that individual. It asks for supportive decision making, where those with disabilities that might impact upon mental capacity are afforded the opportunity through competent and

Box 2: Article 12 Extract of UN CRPD

"States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of 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. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests."

impartial assistance to arrive at decisions that best reflect their own preferences and interests.

The UN CRPD does need to be considered in respect of how it is actually implemented in practice. This is because (as with many human rights conventions) it is a high level framework that needs to be concreted in such a way as to fit with a wide range of jurisdictions, rather than a specific and exact list of steps that need to be taken. We therefore explain the kinds of provisions that occur when this is implemented in domestic law, taking English law as an example.

English Jurisprudence

Since 2010, the primary piece of legislation is the Equality Act (2010)^v, which includes a wide range of protections and rights for people with disabilities. There are two duties that are particularly relevant from this act: the Public Sector Equality Duty (PSED) and the duty not to indirectly discriminate against disabled people. The former is found in Section 149 of the Equality Act (2010), and states that public authorities, including Higher Education Institutions (and agents thereof) shall give "due regard"^{vi} to the following concerns:

- *eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;*
- *advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;*
- *foster good relations between persons who share a relevant protected characteristic and persons who do not share it.*

The other strongly relevant aspect of that Act is the duty to not indirectly discriminate against people with disabilities (and other protected groups), provides under Section 19 (which institutions are obliged to pursue effectively under the PSED. Core to this provision is that: "A person (A) discriminates against another (B) if

A applies to B a provision, criterion or practice which is discriminatory in relation to a relevant protected characteristic of B's ... a provision, criterion or practice is discriminatory in relation to a relevant protected characteristic of B's if ... A cannot show it to be a proportionate means of achieving a legitimate aim."^{vii} In practice, this means considering existing practices and how they might disadvantage certain groups (in our case, those with a wide range of disabilities) and then determining how this practice might be changed to correct for this. There is a strong duty to correct a given indirectly discriminatory practice, unless there is some other good reason (or other priority) which make that practice necessary.

The law here presents rather insistent demands that appear not to be met by many institutional Research Approval Procedures. These demands both mean that institutions – taking into account the implications of academic freedom (namely that researchers have some choice in what topics they actually decide research) – need to proactively promote, rather than deter, research in sensitive settings as it relates to disabilities, and only place barriers in the way to the extent that it is *strictly necessary* to do so. Any barriers should be constructed as to be minimum impact as possible, in line with proportionality. (A similar duty would apply to Academic Conferences, as well as to public funders of research, although these are not considered here.)

The other piece of legislation of concern is the Mental Capacity Act (2005), which under Sections 30-34^{viii} provides a series of legal requirements that must be met when performing research with those who may lack mental capacity. This legislation is perhaps more protectionist in nature than the UN CRPD has in mind, and places strong, but explicit protections upon those with disabilities who might be subjects of research. Surprisingly, whilst researchers are referred to the Act

itself, there is scant training on its implications. For example, the case of *ZH vs the Commissioner of Metropolis* found that lightly touching someone with a capacity limiting disability was 'battery' even when it was believed necessary by the police officers involved, so a simple case of attaching a wristband sensor to someone who lacked capacity is almost certainly an offense (and potentially a criminal one, depending upon the facts), unless this was approved in advance by due process. Whilst there are no substantive judgments to date on Research Ethics, the Court's approach towards reasoning, and evidence of its rigor of thinking, can be found by exploring public judgments on BAILII.^{ix}

A Better Research Approval Process

The legislation outlined in the previous section provides a means to reform existing practice, likely with benefits well beyond disability. The overriding consideration is ensuring that people are incentivized, rather than deterred, from pursuing research that assists disabled people in sensitive settings or otherwise. Below are a number of example reforms that might be achieved.

Qualified Reviewers for Research Approval

One substantive issue is that it is difficult to know whether or not those performing review of proposals have sufficient knowledge and experience, or indeed any experiential understanding of the population or setting at hand, given that this can only be acquired over a substantive period of time (rather than a procedurally oriented training course). A randomly selected Mathematician or Chemist – unless they themselves were subject to particular life experiences – likely has no understanding of the intricacies of particular disabilities, or the risks or disadvantages that arise from different research methods applied to these groups. Yet under existing systems, they are just as likely to be reviewing a given proposal as a HCI researcher with the necessary contextual knowledge. By contrast, a lawyer working in

the Court of Protection (or another sensitive area of law, e.g. Family) would have such experience, as well as the expertise to make challenging ethical considerations fairly and efficiently^x. We might imagine a situation therefore where such specialists could be invited to review such ethics applications. The core advantage is that this process would serve as an adequate and effective check of proposed research projects, ameliorating the current issue of unqualified reviewers considering sensitive settings, thus removing a key deterrent for this kind of research.

Clarity and Precedent

Another core issue is the lack of published reasons given for decisions. Existing processes involve the repeated reconsideration of similar cases, both wasting time and resource, as well as potentially leading to inconsistent reasons and conclusions. Making the decisions as to what is permitted public allows their reuse; it also means that researchers can plan projects in full confidence that they are likely to be approved. Open processes also have the advantage of providing confidence in their fairness. They also have a greater degree of consistency, and thus predictability, negating the need for researchers to design their research based upon a guess of what a research approval procedure might potentially decide. This would erode a further barrier for research involving those disabilities that are less likely to be sensitive, and allow the existing resource currently expended upon such applications to instead be focused upon the more sensitive ones, thus providing more effective safeguards and guidance, especially for researchers who wish to newly include people with disabilities in sensitive contexts.

Provision of Independent Support and Counselling

Disability Discrimination Law is an avenue towards obtaining funding for the necessary support to enable researchers to feel confident in challenging settings.

Initially this might involve funding communities or networks for experience sharing or mentoring of researchers who choose to take this route. It could also include the provision of counselling and other emotional support for those conducting research. The legal purpose would be to promote the inclusion of disabled people in this kind of research. Indeed this route could provide a wide range of further opportunities, and be a route to funding for a range of activities that support researchers in sensitive settings, including on occasions beyond disability-centric cases.

Alacrity in Research Approval Procedures

Existing undue delays to approval are a clear obstacle to research in respect of people with disabilities, potentially preventing the capitalization of immediate opportunities, or the effective modification of research in response to events as they unfold. Moreover, such an approach effectively prohibits undergraduate projects with sensitive groups, because by the time the research has been designed and the approval has been awarded, then

ⁱ Throughout this article, I refer to what are usually known as 'ethics procedures' or 'IRB's' as research approval procedures. I do so because these procedures are rarely grounded in or concerned with actual ethics *per se*, and more realistically represent an approval process that must be completed in order to get "an official seal of approval" in order to conduct a particular research project.

ⁱⁱ To emphasise this point further, it is almost unheard of for a project to be returned for **not** including a group of under-presented minorities; indeed projects not involving vulnerable populations normally gain automatic approval, at least under the system practised at both my current and previous institutions.

ⁱⁱⁱ <http://deevybee.blogspot.co.uk/2011/12/nhs-research-ethics-procedures-modern.html>

^{iv} <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

^v This legislation does not only apply to people with disabilities, but to those with other protected characteristics. Thus, the arguments in this paper would extend to a wide range of other groups as well. However, given that these provisions are more powerful in the disability context, and that disability discrimination legislation alone is sufficient to impose changes to existing processes, it is not necessary to consider this wider issue for the purposes of this short position paper.

the research is already complete. This issue is also largely addressed by the foregoing proposals; precedent removes the need to (repeatedly) consider certain common cases, whilst legally qualified reviewers can be sought for advice on an efficient timescale. An upper limit of two weeks for an initial first instance decision could easily be achieved, revisions could be achieved in a matter of days (or even hours in emergency cases involving researchers already in the field) which would be a great improvement upon under the current systems in place.

Conclusion

This submission has introduced Disability Discrimination Law and how this could apply to the development and implementation of Research Approval processes. I look forward towards engaging further with the ethical issues that emerge in the workshop itself, and how they may also be considered from the perspective of these legal provisions and learnings.

^{vi} The due regard test may well be best understood by reading the (topical) case *Hurley and Moore vs the Secretary of State for BUIS* from paragraph 66 onwards:

<http://www.bailii.org/ew/cases/EWHC/Admin/2012/201.html>

^{vii} There are other limbs of this test, mostly relating to the comparative test. Readers may want to peruse the entire section, here:

<http://www.legislation.gov.uk/ukpga/2010/15/section/19>

^{viii} <http://www.legislation.gov.uk/ukpga/2005/9/part/1/crossheading/research>

^{ix} The Court of Protection database can be found here:

<http://www.bailii.org/ew/cases/EWCOP/> This author recommends some judgments as being of particular interest for the reader who might be interested in delving deeper: *Re P (2014)* which explored whether or not someone had Capacity to Tithe Inheritance: ; *in the Matter of Manuela Sykes*, which concerned a retired Labour Party Politician with Dementia and their care and living arrangements.; *Re RGS (2012)*: which addressed court conduct of someone with a psycho-social disability and *Sandwell Borough Council vs RG and GG*, which examined capacity to marry for those with learning disabilities.

^x Consider the cases and their resolution as documented in the foregoing end-note as evidence of this point.