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Public health, research and rights: The perspectives of deliberation panels with politically and socially active disabled people

Points of Interest

- This study focuses on five consultation panels where politically and socially active disabled people and public health professionals deliberated changing relationship between public health and disability.
- It examines the experiences of disabled people with public health policy, programmes and interventions.
- We argued that using Article 3 of the Convention on the Rights of Persons with Disabilities (CRPD) might lead to more ethical research building on synergies between public health and disability.
- Three of our panels argued that any rights based tool or decision aid to guide public health research and evaluations had to be based on a social model of human rights.

Abstract

Public health research purports to provide the evidence base for policies, programmes and interventions to improve the health of a population. However, there is increasing awareness that the experiences of disabled people have played little part in informing this evidence base. This paper discusses one aspect of a study commissioned by England's National Institute for Health Research (NIHR) to review the implications for public health of theories and models of disability. This part of the study focused on the development of a tool or decision aid to promote ethical inclusion of disabled people in public health randomised controlled trials (RCTs) and evaluative research. The tool was introduced at four regional 'deliberating panels' involving politically and socially active disabled people. In addition, we held a panel with public health professionals. The deliberation panels debated how the focus of public health was narrowing, why disability was excluded and positive and negative issues with using rights to guide research and evaluative practice. Politically active disabled people argued for a social model *of* human rights to guide any rights based tools or decision aids in public health and disability research.

Keywords: disability, public health, evidence, rights, research and social model.

Introduction

Public health is concerned with promoting and protecting everyone's health (Winslow 1920) through a focus on, "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life" (WHO, SDH 2008). Public health therefore has an inclusive remit (the health of the whole population) and an orientation to causes of health lying beyond the health care system. Together, these features of public health have made addressing social inequalities in health central to its mission (WHO, SDH 2008). At first glance, there is therefore a strong synergy between the perspectives underpinning public health and the wider disability movement; both are concerned with socially-generated inequalities in people's lives and with the potential for inclusive policies, to improve the health and thus wellbeing of those whose lives are structured by systematic disadvantage. It might be expected that research links between the two disciplines would be strong, particularly given the increasing emphasis on public health policies that are user-informed and evidence-based. However, despite an increase in research on the relationship between disability and public health (Oliver 1998, Lollar and Crews 2003, Sherlaw et al. 2014, Bickenbach et al. 2016) and inclusion in research (Feldman et al. 2013), there has been little dialogue between public health researchers (who count or measure what disability is) and politically active disabled people (who make explicit how disability is lived) (Ginsburg and Rapp 2015). Instead, there appear to be significant points of tension.

One such tension is the long-standing concern within the disability movement about the classifications of health and functioning used in research. For example, the use of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organisation (WHO) (WHO 2011) and by researchers (Bickenbach 2011, Koutsogeorgou et al. 2014) has been criticised by politically active disabled researchers (Oliver and Barnes 2011) as in effect an espousal of a medical model. The ICF, also called the biopsychosocial model, attempts to bring together social and medical models of disability. It is a framework that makes a distinction between body and structure, taking into account activities (tasks and functions) and participation (in daily life), in addition to the impact of social and environmental factors. However, the ICF only attends to disability and functioning in the context of health and thereby posits a healthy able-bodied norm which politically-active disabled people find problematic. As such, public health policy and practice has tended to view disability as a delimited and specialised medical issue (with associated costs) mainly in terms of clinical prevention and/or rehabilitation into the workforce; instead of the promotion of everyone's health. (Oliver 1998, Arnesen and Nord 1999, Krahn and Campbell 2011).

A second area of concern relates to the place of randomised controlled trials (RCTs) in the generation of evidence for health policies. Trial-based studies of the general population often apply various forms of exclusion, for example by discounting participants with mental health issues or intellectual disabilities (McDonald and Raymaker 2013). Yet, while no longer inclusive of the whole population, it is assumed that the findings are applicable to *all*

adults and/or children. (Feldman et al. 2013, 2014). Implicitly, this also sends the message that disabled people are outside the realms of the 'human' to which such research is relevant. Even when thinking about inclusions in research there are differences. Public health researchers define inclusion narrowly in terms of participation in a trial or even evaluation, whereas politically active disabled people tend to understand inclusion more broadly, also in terms of advocacy in policy (Krahn and Campbell 2011).

A third point of contestation is the different framing of the concept of an 'intervention' in public health research. Public health researchers view interventions as necessary measures: to reduce threats to population health (e.g. traffic calming in residential areas or reduction of sugar in drinks); to increase access to health promoting environments (e.g. play space for children); and level up inequalities in health (e.g. early years' interventions for children in poverty). Despite this, for politically active disabled people, some public health interventions are still predicated on professional surveillance and (bio) medicalisation of health, and can imply that disability is a pathology that needs to be fixed or rehabilitated (Oliver 1998). There is a lot of complexity, but some disabled people point to the historical links between public health and the legacy of eugenics and colonialism (Bashford 2004), as well as to the difficult ethics involved in contemporary reproductive choices, such as prenatal screening (Shakespeare 1998, Kerr and Shakespeare 2002). This does not mean that politically active disabled people are against public health choices or interventions *per se* but that they think it is important to employ a critical stance towards the theoretical underpinnings and implications of 'interventions'. (Oliver 1998).

In practice, such points of tension mean that the public health and disability research communities occupy what can amount to adversarial silos with very little cross-cutting research from which to build a common agenda. There has, however, been an increasing appreciation of the need and potential for public health research to draw on, and engage with, disability rights perspectives that view disability as part of *every* human experience (Titchkosky 2014). In the United Kingdom (UK), an important driver has been the wider equality agenda, for example as enshrined in the 2010 Equality Act, which sets out nine 'protected characteristics' (inclusive of disability) and requires certain duties from public services to ensure equal access and fair treatment. Yet, despite this legal framework, Coalition/Conservative government austerity policies and welfare reform have negatively impacted on public health. The theoretical basis and model for these welfare policy reforms has been discredited (Shakespeare et al. 2017) and there is evidence that the recent tightening of welfare eligibility and reductions in services are causing ill health (Bambra and Smith 2010). This is occurring against mounting evidence of health inequalities experienced by disabled people, including those with mental health conditions (Chesney et al. 2014) and intellectual disabilities (Heslop et al. 2014). Rather than inevitable consequences of their designated impairments, these health inequalities arise from socially-determined factors affecting how people live and the limited healthy 'choices' open to them. Researchers are therefore increasingly debating what public health paradigms should consist of, who the

focus should be on and what differing methodological perspectives can bring to reduce health inequalities (Garthwaite et al. 2016).

Against this background, England's major health research funding agency, the National Institute for Health Research (NIHR), issued a call for a review of the implications of models and theories of disability for public health research (NIHR, 2013). Our team secured the contract for this scoping review, with inputs from panels of politically and socially active disabled people and their organisations, as well as public health professionals. Together, we wondered if there was a way in which human rights paradigms could be used to build an ethical bridge to improve the inclusivity of public health research, making it relevant to disabled people's lives. While historically human rights have sometimes been in tension to disability rights, influenced by Feldman et al. (2016), we used the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006) to develop ethical tools and decision aids that could help to make public health research more inclusive of disabled people, as well as empirically stronger. The CRPD is an international human rights treaty and innovative legal instrument that also enshrines protected characteristics but assigns disabled people 'rights' which governments and public bodies have duties to uphold (UN 2006). We focused on Article 3 of the CRPD which encapsulates the general principles of the convention (see Appendix 1). We condensed these principles to dignity, inclusion, intersectionality, accessibility and equity, and these informed the tools that research commissioners, research teams and research participants could use to guide and evaluate research. This paper focuses on the way in which our initial proposals were introduced at four regional deliberating panels involving politically and socially active disabled people. In addition, we held a panel with public health professionals. We wanted to know if we could build on synergies between public health and disability communities and interests, and if existing tensions still mimicked those found in the literature identified above. The aims of the panels were thus to deliberate the changing relationship between the public health (and public health research) and disability communities, and to explore whether using a human rights tool would lead to better research. We explain how we went about this in what follows.

Methods

Ethical approval for this aspect of the study was granted by the Health Sciences Governance Board at the University of York. The empirical part of the NIHR scoping review took place during late July and early August of 2015 and consisted of five deliberating panels (see Berghs et al., 2016). Essentially a consultation exercise, deliberating panels can act as a means for democratic debate on an issue (Abelson et al. 2013). We thus used deliberating panels because they mimic citizen advice or jury panels (Crosby et al. 1986) but situate disability and public health communities as part of a consultative and 'deliberative' democracy (Barnes 2002, Abelson et al. 2013).

Citizen advice or deliberating panels have been used in public health, health care and social policy contexts (Blacksher et al. 2012). They were implemented at a time when there was criticism of lack of insight into the way in which healthcare resources were being used (Harrison and Mort 1998). Yet, Harrison and Mort (1998) warn that inclusion of people within decision-making in health care policy, for example in public and user involvement, can act as 'technologies of legitimation'. Policy makers and managers are not bound by the findings of consultations and panels can give the illusion of 'choice' (Harrison and Mort 1998). While mindful of such criticisms, we considered that deliberation methods can be useful in terms of opening up critical debates especially if they become linked to the development of research ethics and methodological tools. Panels place disabled citizens as experts in that process, in that they were advising researchers, public health professionals and commissioners. Similarly, we ensured that we had a public health professionals' panel to situate advice in relation to current public health practice.

We engaged four partner organisations to organise and recruit participants. Organisations were geographically spread across the country in London (Inclusion London), Manchester (Greater Manchester Coalition of Disabled People), Sheffield (BME Network) and Leeds (Sisters of Frida). The organisations were user-led, small, locally run and often located in areas linked to social disadvantage and deprivation, like Brixton (London) and Moss Side (Manchester). Participants were all given information sheets explaining the study and a copy of the tool before any discussions (See Appendix 1). Organisations were given recruitment fees and the participants paid a fee plus travel expenses. Before each deliberating panel began, participants were asked if they had any questions about the information sheet, study or the researcher. This was done individually and as a group. They also signed a consent form and participants were assured of confidentiality. A representative from the partner organisation was present during panels and acted as co-moderator in keeping with the role of the DPO as partner organisation. The deliberating panels were recorded and lasted between 60 and 80 minutes.

The DPOs were responsible for a sampling strategy that aimed for diversity but where political or social activism was thematically important. In total 30 people participated from a wide range of backgrounds, and a mix of 4 professionals who were involved in public health decision-making (see Table 1). By politically and socially active, DPOs included disabled participants who had political and social roles or were involved in community activism or work. There were a wide range of people with various impairments and conditions. The DPOs ensured that parents of disabled children, young people and carers were represented, along with those with hidden disabilities, undiagnosed conditions, fluctuating conditions, multiple impairments and mental health issues. A range of ages was represented from young people to pensioners, differing socio-economic and professional backgrounds and sexualities. There were also people present who did not ascribe to an identity of 'disability' and saw themselves as socially active in community life rather than politically

active. The public health professional representation was low in contrast to the participation by socially and politically active participants. The feedback that we got from Inclusion London, responsible for organising that panel, was that many professionals viewed disability as a specialised issue and not part of their remit. This did not reflect the views of the professionals who participated. They were critical and concerned.

Table 1

Deliberating panels were digitally recorded, transcribed, anonymised, and then analysed using the qualitative software package NVivo. The object of coding was not to go on to develop theory but to understand the relationship between public health and disability, as well as the extent of acceptance of use of rights as an ethical tool or decision aid. We explain our findings next.

Findings

All participants, inclusive of professionals, framed public health within a context of cuts and government polices linked to austerity. Often participants did not make clear distinctions between NHS services, nor relationships between health and social care to public health. Participants viewed extant services as contributory to understandings of public health. Before they could speak about public health or improving public health research, they implicitly described how 'health' in England had been adversely affected by economic policies.

Politically active disabled people related the effects of government welfare changes to new legislation affecting the Independent Living Fund (ILF), Disability Living Allowance (DLA) and Employment and Support Allowance (ESA). They agreed with evidence that the health of disabled people had been disproportionately and negatively affected by benefit cuts and new taxes, such as, for example, what is known as 'the bedroom tax' (a penalty for under-occupancy of homes) (see Kaye et al. 2012). All felt unfairly targeted by these policies and vilified in the media in terms disabled people being represented as a 'cost' and 'burden' to society. Public health professionals too related very difficult and emotional pressures they were under to try and ensure funding for frontline generalised and specialised public health services. It is against this background that participants deliberated what public health was, what public health research should focus on and the role human rights tools could have in making research more ethical. Three interrelated themes came to the fore: 1) how the space of 'public' had changed, 2) how an ethics of exceptionalism linked to disability exists in research practices and ethics, and 3) the limitations of human rights models. We address each in turn.

'We had it and they cut it': Redefining the space of 'public' health research

As stated above, deliberations began by asking all participants to give definitions of public health. A female public health professional began discussions in her panel by stating:

> *I mean public health, for me, is all encompassing, from prevention to awareness of what helps to keep us well. And promoting good health, through to living with whatever condition you have in a healthy well way; and it takes into account all of the broader things in life that impact on physical wellbeing and mental health wellbeing, from the environment that you live in to your upbringing, to your circumstances, to culture, to disability, all of those bits. That's what it means for me; and it's the messaging that goes around that and getting people to access things that enable that to happen.*

This kind of definition was qualified by politically active disabled participants. They nuanced that you could not be too idealistic or negativistic about public health. Several participants mentioned vaccinations and the eradication of viruses, like polio, as positive. Yet, participants also noted a need to remain vigilant over public health initiatives, due to both past and present government policies. A participant explained:

> *Well, I think the positive side that certain conditions and diseases have been eliminated because of mass immunisation; that would be a positive. I think universal access to health services is a positive… as long as they don't get screwed over by the government any more…. So those are positives…. The negatives are what I've just said, which is government interference, which puts … intolerable conditions upon the medical profession, and also… people wanting to use services.*

All participants also noted that while a more 'holistic' public health was what they wanted, they felt that such a focus did not correspond to present realities. They thought that instead of public health focusing on the creation of 'inclusive environments' and battling 'health inequalities' it was becoming politically restricted. A female disabled participant in panel two explained, "I suppose the question I would ask is are we talking about the government's very narrow definition of public health?" Another disabled female participant in panel five elucidated:

> *It's a fragmented view that is pushed (…) you'll have a few of a certain section [of the population] and they'll be, like, 'this is the public', you know, health issue du jours, and then there'll be another [public health intervention] but they won't treat them as if they're joined together; it'll be treated like it's just one [that[the spotlight's thrown on.*

In this way, what was constituted as 'public' in public health was redefined in terms of specific health issues that had political backing or champions, such as 'dementia'. A female participant in panel four said, ''Public health means, to me, access to any provisions made available in regard to my health." All participants who were not professionals noted that as 'minorities', whether as disabled people, women or people from BME groups, public health was evaluated in terms of what they could 'access'. They felt that public health was not constructed in terms of 'deservingness' of that access, nor real 'need' for resources, but in terms of cost. They noted how public health discourses were focusing on individual responsibility, and were thus victim blaming if you had specific conditions like diabetes, were obese, or smoked. Public health issues, like obesity, were thus constructed as if individuals had control over environmental risks and social choices freely.. Participants who had severe long term illnesses, mental health conditions, and/or fluctuating and/or undiagnosed conditions explained that they felt neglected by public health promotions, and that they were sometimes treated with suspicion. They noted that even in public health research, the emphasis was often on short-term 'recovery' from disability together with aiding people back into the workforce. Across groups, participants argued that 'recovery' was usually not possible, and many believed they would have public health needs along the life-course.

This meant that participants reported having conflicting emotions and fears about using both health and public health services. They noted feeling 'judged negatively' because of having impairments and/or health issues, that is, judged for deviating from an able-bodied and healthy norm. One participant noted that as well as dealing psychologically with able-bodied judgements of her health, and linked physical handling of her body, she had to deal with stigmatising assumptions about her contributions to society and ability to work. This was upsetting because she contributed by juggling considerable stressful administrative responsibilities, emotional work and training of her personal assistants. The increasing bureaucracy of staying independent and being an employer was now perceived to be causing her ill health but this was not viewed as relevant to public health, despite being linked to 'work' for her.

Participants also gave examples restricted public health choices and access to spaces due to lack of dignified treatment. Participants in panel four used especially strong language in this regard, like 'scrapheap' and 'forgotten'. A female participant said:

> *Well yeah, but they don't care, do they? They don't! You know, it's all about, again about funding isn't it, there's not enough funding for general needs. So, be honest, you know, we are neglected, and they're not bothered, and that's putting it mildly.*

She noted how there was no longer a moral duty of specialised care for disabled people when funding for general needs of the population is not assured. Hence, participants often

debated how the relationship of disability to public health had changed in several ways. A male participant in the second panel noted how the public health system was not designed to deal with the complexity of long term conditions and so had to focus on 'crisis intervention' instead of a 'community led long-term health and wellbeing service'. Interventions were also focused on individuals and 'fixing' , 'rehabilitating' or 'curing' rather than living healthily 'with' disability.

Disabled participants explained that research was needed mainly because public health professionals got 'the basics' wrong. This meant that research occurred 'downstream' instead of upstream in assuring health promotion and secondary prevention of illness, with integrated health and social care services. All panels noted that basic public health information was inaccessible. Nor was it always culturally or disability sensitive. For instance, a moderator gave the example of her d/Deaf friend who had diabetes but could not access DSL information from Diabetes UK about her condition. In the same panel, another example, by a woman in a wheelchair, was given of inaccessible screening services. She said: "And really inaccessible stuff like breast screening and all of that kind of thing, which happens in vans with wheels upstairs." Other participants noted that information, understanding and representation of the diversity of disability was missing. One woman in panel five stated:

> *I think that lack of awareness of other types of disability, other types of physical disability, other types of sensory or cognitive impairment are really not tackled in public health discourse very much. I think it's all people stood round smiling from different ethnic minority groups and a person in a wheelchair.*

A female participant in panel two noted that to understand the creation of health inequalities, for example, amongst people with learning difficulties, you had to understand legal principles like 'best interests principles' and how decisions were made by professionals. Participants in panel four noted how professional assumptions about disability and UK culture often shaped research. They gave the example of outdoor walking programmes. This presupposed people had money for walking shoes and clothes, access to transport and green spaces, were able-bodied and would enjoy being outdoors rain or shine. They shifted the focus of inequalities research to the practices of public health professionals. Participants in panel three pointed to professionals shaping access and public health practices in able bodied terms. They thought disabled people still lacked autonomy over their own decisions, bodies and access to health, dental care and public health services. They also spoke about diagnostic overshadowing with professionals often focusing on impairment instead of illness or health.

All participants noted how 'disability' was still viewed as a specialised issue, increasingly separate from rare diseases, chronic conditions, and even impairments gained, for example, through aging. They also argued that it was very rare for multiple impairments and physical

and/or mental health conditions to be treated together. Similarly, they noted a rise in the quantity of medical diagnoses and definitions. This became prevalent in common mental health conditions, such as depression, that were treated by pharmaceutical regimens. Despite several participants noting and giving examples of how holistic approaches to health and public health worked better, a young BME woman related how she was 'put on pills' for years and 'forgotten' while another woman who was suicidal explained being on 'multiple pills'. Some participants felt this increasing medicalisation also bureaucratically limited definition of 'disability' and thus any related welfare benefits. A male participant in panel two explained that disability, "becomes more and more exceptional cases". He argued that there was instead, "an uprising of medical conditions, medicalising what I think are just part of a continuum, a healthy continuum." Participants in panel two and four were very critical of the increasing involvement of the private sector in public health. A female participant in panel four stated, "There's a lot of sharing of the poor people's wealth that goes on in these CCGs", noting how it was GPs in Clinical Commissioning Groups (CCGs), sometimes with ties to the pharmaceutical and other industries, that were responsible for public health decision-making in local authorities.

Similarly, people who had fluctuating, invisible or medically undiagnosed conditions noted how the bureaucratic confirmation of a condition as 'disability' was being medically delimited for them. For example, people diagnosed with long term illness noted a shift towards a medical assessment of incapacity of work. Yet, they also explained that access to health and public health was undiscriminating if you could pay to go private as some participants had done. Participants thus felt that public health was increasingly linked to professional gatekeeping, socio-economic class and resources. Inequalities were perceived as widening for many of the participants and they felt improved public health research was crucial.

Ethics and research exceptionalism

All participants related that there was a big need for better and more ethical inclusion in public health research. Professionals emphasised how they used public health research evidence to implement and inform policy decisions along the life-course. However, one professional stated that she often struggled to find public health research linked to intersectionality between disability issues like mental health, gender, ethnicity and entrenched poverty. Yet, despite the nuances that professionals were making linked to inequalities and noting that things could be better, they did not make the step to the co-production of research. Many disabled participants pointed out while they appreciated involvement this was the very issue they had with this project – why were the agendas and definitions of disability set without them?

Representatives of DPOs also felt they were never involved from the onset but asked to aid afterwards, for example, with recruitment. A participant noted how inclusion and participation were 'buzz words' but rarely meaningfully implemented. A participant in panel

five related an instance of open bullying. The head of one DPO explained how their current need for funding often forced participation on any terms. BME participants noted that although, according to human rights and equality legislation, ethnicity was supposed to be a 'protected characteristic', funding constraints meant that this was not the case. In fact, they often felt in competition for public health resources with other characteristics, such as disability, and did not want to form alliances because it was too 'exhausting' at the moment. This limited cross-cutting alliances, activism and intersectional research.

A BME participant wondered why, if they represented a certain section of a population suffering from health inequalities, they were not given a percentage of equal public health representation in local councils, on CCGs and within public health research.

> *Because I don't want to be told by a non-person of colour that the service provision is adequate for me; even though the death toll is rising, the actual service provision is adequate. I don't wanna be told that any more, that's long gone. We need to get rid of the frontline racist service provision that we have. Racism always comes in a recession, and if you are a person that's protecting your own purse strings so you have a job, you're gonna be racist too. So we need to have a fair access, and if they're not gonna give us the positions, because it can't just be one colour face at that level, there, the services need to be adequately monitored, evaluated and heads must roll.*

Several disabled participants across panels felt that they had been involved in research as a 'token' disabled person but thought this was also illusory as their experiences were unrepresentative of the heterogeneity of disability. Other participants argued they needed to be involved in academic and NHS committees and had issues with the way in which ethics committees are structured. A woman in panel five explained:

> *The way that research ethics committees work is that genuinely, if you have any kind of mental health issue or cognitive impairment or psychosocial disability you can't be involved unless you're gonna jump through a thousand hoops (...) The entire structure of how research is conducted excludes disabled people from participation in it and I think there is a fundamental shift that needs to, okay, in universities, at the national research ethics committee levels, to recognise disabled people as being completely able, a lot of the time, much more than the current system gives them credit for, to be involved in research.*

Participants in panels three and four reported that they had been involved in research but not empowered to do their own research. They also questioned what was happening with the findings. Many participants felt that the problem with research was lack of implementation and called into question 'academic impact'. Panel three noted a mismatch

between qualitative research geared to the theoretical concerns of academics and quantitative research that worked according to medical models upholding the status quo. Panel four raised concerns about how an instrumental environmental focus in public health research has neglected socio-cultural complexities and was becoming discriminatory.

Hence, participants believed public health research had to change because as a male participant argued in panel three, "People are setting policies with absolutely no idea of the issues that they're actually dealing with, and have no personal experience of." When asked about what public health research they wanted, participants in panel four had a hard time in answering because they were so concerned with accessing limited public health resources. Other panel participants raised issues like lack of organisation of health and social care for disabled people, to concerns about addressing health inequalities linked to intellectual disabilities in particular. They argued public health research had to be focused elsewhere.

A male participant in panel two explained, "I mean I would see it as like something that, issues around housing and stuff that are once again becoming a real wider threat to health and also like some of the issues of poverty." A woman in panel three explained:

> *I'd be very interested to see any research done about the impact of all the cuts in services and benefits to people's health, you know, because obviously there's a massive change in social care provision and there's a massive change in benefit provision and what actual impact that will have had, because it obviously will have had an impact on people's physical health, and also on people's mental health.*

A participant in panel two explained that claims of 'objectivity' were often used for research not to be too overtly political or social in nature and this was why disabled people and DPOs needed to become involved. He said:

> *I think it's one of the reasons that disabled people, you know, we have been saying there needs to be clarity and a level of inclusion (…) become part of what is going on rather than just being, you know, asked a few questions and then that's it.*

Participants also noted how all research, inclusive of RCTs, often struggled with not only lived experience but complexities of disability. If they had mental health issues or severe impairments, disabled people were conceptualised as 'vulnerable' and thus ethically excluded from trials. A woman in panel five explained:

> *You get regular emails around asking for people to take part in psychological research, cos there's always psychologists trying to do tests; and I'd always emailed back and say and I have a mental health problem, and most of the time people would email back and say, "Oh no, sorry, you know, we'll exclude you." (…) All these people are coming up with stuff about what they think, you know, the mindset of people is, but actually don't include a whole chunk of people.*

All participants noted that when research was done well and they were involved according to best practices of patient and public involvement (PPI) this could be mutually beneficial. A participant in panel five explained:

> *And what we're finding is that, because we have PPI on most of the trials as well, a lay member going on there, we're able to influence part of that but it's a very slow process, but they are seeing, the researchers are seeing the benefits from it as well.*

Another participant in panel three who was involved with research nuanced involvement in terms of accommodation:

> *We were asked our opinion, we gave our opinion, and they came back and had accommodated it, if it was possible, and if they could, didn't accommodate it, they explained why (…) I wouldn't want just to be there, I would want to know that my input was listened to, as well as, not more than anybody else's but as much as anybody else's. And, as I say, for me that, the user group was brilliant because, you know, they, we changed a lot.*

While some participants made suggestions about methodological changes in research to accommodate disability, none of the professionals did. They noted costs instead but the DPO moderator in panel two challenged their knowledge on funding grants to ensure accessibility. It was noteworthy that both professional assumptions and research 'ethics' were delimiting disability involvement, not only as participants but co-producers. We asked if a human rights framework could aid better ethical inclusion?

'One of our old slogans was rights not charity': Limitations of rights in research

Deliberation panels discussed whether we should use a human rights tool based on Article 3 of the CRPD (UN 2006) to try to ensure more ethical inclusion in RCTs. One of the first issues that all participants pointed out was that human rights had to become more accessible. Yet, they also noted how simplifying rights for researchers, commissioners and professionals had certain dangers. A woman in panel five stated:

> *If someone isn't disabled or isn't a disability rights activist and you say accessibility to them, they'll probably think yes, it has a wheelchair access. Do they think, is it in large print? Is it easy read? Are there pictorials? Is it audio available? Is it video available? The, all of that is accessibility. And… maybe you need almost like just a, an example list of things for people to check off, because I think you're aware of the… I completely see the benefits of simplifying it, I get it, but I think there's a risk with*

allowing people to tick yes, we installed a wheelchair ramp, as a blanket for yes, we conducted accessible research.

They also noted how a "one size fits all' approach linked to human rights may not work, and definitions of key concepts were often contested. Likewise, national and international conventions may clash and professionals may not be aware of the CRPD. However, human rights, as a concept, also seemed to be the common ground that everyone agreed on. It was creating discussion, for example, on what principles like accommodation meant and how to ensure research had impact. A professional thus stated:

So, I wonder if there's a human rights approach to be taken, it needs to be considered in the round and it needs to be championed at a very national level, so it balances out a very negative mantra that you have about disabled people; and in fact maybe the way you frame it isn't just around disability, you frame it around kind of equality and inclusion in its broader sense, because if you thought about dignity and inclusion, you know, you could maybe not consider disability but you might consider how it impacts on race, sexual orientation, gender reassignment and all of those sorts of things...

While professionals treated human rights as instrumental to research in general, disabled participants felt that their rights now needed to explicitly become an ethical necessity. During the deliberation panels, disabled participants recounted instances of disablism, discrimination and shared experiences where their public health rights and dignity had been denied. Many of these instances were gendered and, for example, linked to lack of reproductive choices. For example, in panel five, a female participant poignantly related how important it had been to be asked by a health care professional about her sexual health. She said: "I felt, (*they*) spoke to me like a human and a woman, and gave me a choice and that was only a few years ago that that happened." Another participant related, "One of my friends who's wheelchair bound was told by her GP that she didn't need to go on the pill because she's in a wheelchair; she shouldn't be having sex." Other instances involved outreach programmes linked to sexual health for young girls with intellectual disabilities being cut, disabled people being told that they should be catheterised, continent people being forced to wear incontinence pads and people with life-limiting conditions not having access to warm homes, correct care, as well as access to life sustaining medications ending and deaths occurring. Panel four argued issues intersecting with BME ill-health like the impact of incarceration or racism were ignored. Panels three and five noted concerns about women with intellectual disabilities prevented from having children or not being able to keep the children they had. A participant in panel five stated:

So it's contraceptive help, it's the parenting support through the social welfare system, is clearly failing the mum with disabilities in relation to motherhood and

parenting. I think there is a really huge problem with public health with failure to adequately support disabled people to be parents.

While some participants felt that using rights gave them a stronger footing in research, other participants also noted how human rights legislation and definitions in England were being watered down, especially linked to principles of humanitarianism. A BME participant argued:

If a person that's fleeing from a war-torn country is seen to be a problem and, and no-one wants to take care of them, who's gonna protect us? What is the definition now? What is the understanding of the decision-makers of human rights?

Thus, some participants related fears over leaving the European Union, European legal frameworks and the current government creating a human rights bill. It was noted by a BME participant that the government had gotten rid of legal aid, disallowing any form of right to legal redress or protest from the most impoverished. While one participant in panel five stated how rights had protected her, several participants noted that a big issue with the CRPD was lack of education, enforcement and accountability.

Politically active participants and DPOs in panels two, three and five explicitly stated that any human rights approach had to be linked to the social model. The social model makes a distinction between physical, cognitive and sensory impairment and disability as experience of oppression. It was pointed out that the social model lay at the foundation of the creation of the CRPD and rights legislation had been fundamental to the elimination of barriers in society. For example, in panel five, a participant argued that, "Legal capacity or your right to accessibility in the CRPD, none of which are gonna be realised without the social model approach to changing society." In the professional panel, the social model was not mentioned until brought up by the DPO moderator but professionals tended to understand human rights better than the specifics of disability rights.

Disabled participants argued a social model approach linked to rights meant that public health research occurred in a respectful way because it made explicit the ethical conditions of inclusion in research as social. Yet, as illustrated above, most panels felt that human rights abuses had increased and were worried about this occurring in research. A participant in panel five warned:

They try social model, whatever, in the good times, but as soon as the money, everything, their mindset, their systems, switch straight back to medical model which, for a lot of people with disabilities, does not offer dignity, independence, freedom of choice, it's just back to you need to be looked after.

Panel five participants argued about whether it was rights that had to now become linked to the social model to make them stronger or the social model needed bolstering by rights. A participant explained, it seemed they now had general theoretical rights to many things but no real individual rights anymore. Panels noted that a human rights tool might mean they made incremental gains but also were aware how it could be manipulated and abused. They felt that using human rights in RCTs always had to include disabled people as co-producers of research in setting agendas. By contrast, professionals felt that using any human rights tools in research was merely an evaluative exercise and wondered if we were not just adding another check-list. They did not understand how having more ethical research practices could inform stronger evidence and methodologies to impact public health inequalities. They felt that their decision-making was already informed by public health research and did not understand what a disability rights or studies approach could add, such as innovation. We discuss some of the issues this raises below.

Discussion

Despite using deliberation panels, we found there were issues with the ability of such panels to truly reflect the diversity of public health and disability. There are many reasons why this could be the case, such as, for example, accessibility of political and social spaces. This also represents time constraints, restricted number of DPOs involved and limitations within this part of the study. We have to acknowledge public health engagement was impassioned but low compared to disability involvement, as was democratic inclusion of various impairments and identities (e.g. D/deaf community or Lesbian, Gay, Bisexual and Trans (LGBT) intersectionality), with panels biased towards women and wheelchair users. We did not accommodate intellectual or severe disabilities anddid not capture the recommendations of people with impairments, like dementia, that may not ascribe to an identity of 'disabled', 'disability' or even be in the early stages of social and political organisation (Thomas and Milligan 2015). This is not because we did not try to recruit or involve those people through DPOs but our findings remain restricted to the views of politically and socially active disabled people.

As such, while all panels framed discussions on public health holistically illustrating potential synergy, disabled people felt public health was politically narrowing. They located tensions between public health and disability research within the context of how current economic policies and welfare cuts adversely affected their physical and mental health. The links between health, welfare and economic policies have often been neglected by public health researchers (Bambra and Smith 2010) but disabled people, and now some public health researchers (Garthwaite et al. 2016), felt this was salient. Disability was an explicitly delimited administrative category (Stone 1984) and social entitlements, such as welfare provision, had now become linked to inability or incapacity to work (Bambra and Smith 2010). This is a subtle shift in moving welfare entitlements away from medical assessments

of differing kinds of impairment, to of incapacity or inability of functioning to do specific forms of work posited on able-bodied norms. In this way, participants were often subtly questioning the public health focus of our research, and underlying connections to what they felt was a disingenuous social policy focus. Perhaps this was why some participants were requesting research on 'care' and 'support'? It also explains why participants were suspicious of a more inclusive public health research and discussed broader tensions first rather than the specifics of research design or interventions.

While asking researchers to rethink the policy context of public health research it was noteworthy that no participants requested research on *rights* to public health and disability research. Irrespective of impairment, gender, ethnicity and background, all participants related how public health was now viewed in terms of what they *could* access not in terms of what they had a *right* to access. They also related a lack of enforcement of public health rights and accountability, weakening civil society activism and representation in public health. This tells us something about the relationship between public health, disability and citizenship. In the past, both health and public health were viewed as social entitlements of citizenship but if participants relate that they cannot access basics of health and that they are not considered as part of the 'public' nor the ethical practices of public health – this reflects inequalities that are bigger than health alone. This was expressed not in lack of trust but in cynicism towards the public health system. Neither our research nor the NIHR were neutral but viewed as extensions of government bodies and political priorities that, indirectly or otherwise, were possibly linked to cuts which could have adverse consequences. Participants also noted areas in public health, in particular linked to mental health, where privatisation is leading to greater medicalisation and silencing of 'lay' voices (Britten and Maguire 2016). They were pointing to a resurgence of the medical model in public health.

Participants felt this was because public health and research was being constructed down-stream after health inequalities had arisen. Priorities were then also on the short term and cost reduction of those inequalities in terms of medicalised outcomes. They argued that this does not have to be the case and gave examples of good practices. Despite this, participants also noted how ethical inclusions could fragment and limit the expertise of politically active disabled people in favour of research with people who may not or not (yet) be politically active such as people with dementia. Representation and inclusion of certain categories of disability aligned to the status quo were acting as a 'technologies of legitimation' (Harrison and Mort 1998). This has consequences for the way in which RCTs are constructed, for example, in how statistics are collected, what is measured as 'incapacity' and conceptualisation of diversity as well as specialised public health needs linked to disability across the life-course.

Panels indicated that using rights tools or decision aids could be a first step forward in ensuring better public health research but this had to be correlated to the political realities

affecting health inequalities. We argued that linking rights to ethics in research might ensure better methodologies, innovation in tools used (like measuring outcomes) and to ensure a better evidence base for impact. Yet, three of our panels also requested a link to the social model of disability, which although implicit in the CRPD now had to be made explicit. What was interesting about this was that our participants were shifting the paradigm from which we approached public health and disability research. They were arguing for a stronger social model and deliberating if a social model *of* human rights could be the answer to more ethical public health and research.

Conclusion

The CRPD links civil political rights with cultural and social rights. When deliberating public health research it seemed as if participants were indicating how both sets of rights were under attack. All our panels noted the political context in which public health research is currently taking place that delimits access to civil rights linked to health and public health. Politically active disabled people wanted any human rights tools or decision aids linked to ethics in public health research to now explicitly note a social model *of* human rights. This implies theoretically and methodologically creating research to understand how health inequalities become linked to political entitlements and societal construction of disability and disablement.

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Table 1: Details of the deliberation panels

Panel	Location	Participants	Gender	Focus
1	London	4	3 women, 1 man	Professionals
2	London	8	4 women, 4 men	Disability
3	Manchester	8	4 women, 4 men	Disability
4	Sheffield	8	6 women, 2 men	Disability (BME panel)

5	Leeds	6	6 women	Disability (women's panel)

Appendix 1

A Human Rights Toolkit for Public Health Research

What is the study about? Public health interventions which are effective in the general population are often assumed to apply to people with disabilities. However, evidence for this is limited and there is a need for more inclusive and better informed research. Given the public health challenges facing the UK population, it is especially important, to ensure interventions are relevant to people's lives.

Randomised controlled trials (RCTs) are viewed as the gold standard of research in public health and are becoming increasingly influential in terms of policy. Yet, these are not always inclusive.

To address this problem, we want to develop a toolkit to help inform 'disability' sensitive and ethical research. We want your advice on how to develop this toolkit and more specifically, on how researchers can do better research. No prior knowledge of research is needed to take part in the discussions.

Why human rights?   Human rights are becoming increasingly influential in informing how research should be conducted.   Article 3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines these rights as:

  a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
  b. Non-discrimination;
  c. Full and effective participation and inclusion in society;
  d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
  e. Equality of opportunity;
  f. Accessibility;
  g. Equality between men and women;
  h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

What does our toolkit look like? Our proposed toolkit focuses on dignity, inclusion, intersectionality, accessibility and equity.

Dignity	Inclusion	Intersectionality	Accessibility	Equity
How was dignity ensured?	How were people included?	Did they involve people with different types of impairments,,sexualities, ethnic groups, genders or children?	Was accessibility thought about?	What kind of short or long term impact will this have in changing health inequalities?

Why a panel? We are still developing and trying to improve our toolkit. We want to know what you think about it. How well do you think it reflects the needs of people? Will it help researchers to be ethical, respectful and protect human rights?