

## TRANSCRIPT



### Centre for Disability Studies

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#### Title:

**Inequalities, social care and disabled people: does a public health perspective have anything useful to add?**

#### Abstract:

**This seminar will discuss contemporary public health perspectives and ideas, within the context of health inequalities, and determine their significance to current debates surrounding social care and disabled people. Issues discussed during the seminar, include: discriminatory assumptions and operations within contemporary visions of public health; the focus on social determinants in understanding health inequalities; notions of risk within public health and social care; the role of self-directed support to address health inequalities; and effective strategies for public health policy change, including current approaches focusing on inclusive growth. The seminar will consider the role of public health specialists within local authorities, rather than health services, and determine what impact this has on disabled people's participation and inclusion within the local community.**

#### Bio:

**Chris Hatton is currently Professor of Public Health and Disability at Lancaster University. For the past 30 years he has mainly been involved in policy-relevant research with people with learning disabilities, trying to document and understand the inequalities that people experience, evaluate if policies and services make a difference to people's lives, and work with people who can put that evidence to good use.**

**Details:**

**University of Leeds, School of Sociology and Social Policy,  
Research Culture Seminar Series  
6 May 2020**

M Griffiths: Hi Chris, are we okay to start? Are you okay for me to open?

C Hatton: Yes, I am.

M Griffiths: Okay, brilliant. So hello, everybody. My name is Miro Griffiths. I am a Teaching Fellow at the School of Sociology and Social Policy, here at the University of Leeds. Welcome to this event. This is a joint event by the school of Sociology and Social Policy and also the Centre for Disability Studies and it's part of the Research Culture Seminar Series. Let me just explain the programme that you have in front of you, just to give you a little bit more context. You should have the option for raising your hand: at the bottom, there's an icon which has a raised hand motion. You can click that, particularly during the Q & A, to indicate that you want to ask a question. I should say at this point, that you don't have an option to speak at this moment so your microphone is automatically muted and your video won't turn on but when we come to the Q & A, if you want to ask a question, you can raise your hand and I can un-mute you and you can have a conversation with Professor Chris Hatton, or alternatively, you send a message in the chatbox. Make sure that you choose the option to send the message to everybody and then during the Q & A we'll ask Dr Angharad Beckett to read out a selection of comments and some of the overall themes and any direct questions for Professor Hatton to reflect on and respond to. I should say as well, there are no fire drills planned and I've got no idea where the toilets are – you are all individually better placed to determine that for yourselves!!

In terms of the actual session, between now and 1:30 pm, Professor Chris Hatton will present the seminar and then this will be followed by a Q & A for all of you who are interested in asking questions and posting a comment, up until 2 pm. I should say as well that the session is recorded, up until the Q & A: so we will record the first part, but after Professor Hatton has finished his presentation I'll pause the recording and any comments or any questions asked won't be recorded.

So, let me just quickly introduce Professor Chris Hatton. Professor Chris Hatton is a professor of public health and disability at the University of Lancaster. For the past 30 years, he's mainly been involved in policy-relevant research with people with learning disabilities, trying to document and understand the inequalities that people experience, evaluate policies and services, make a difference to peoples lives and work with people who can put that evidence to good use.

It's a pleasure to have you, Professor Chris Hatton. I'm now just going to transfer over to your slide, which hopefully will come on the screen, and I think you have the option to move the slides at your own leisure, so, the floor is yours.

C Hatton:(Slide 1) Great. Thank you very much, Miro, and thank you very much for inviting me to this and organising this webinar. This was originally going to be a face to face seminar, so it's really impressive that you've managed to re-tool it so quickly, for obvious reasons.

So, when we were setting this up some time ago, this was the title that I was going to speak to: Inequalities, social care and disabled people – does a public health perspective have anything useful to add? So I've been doing research involving people with learning disabilities for 30 years and for most of the last 10 years that took a public health turn, involving me much more in the world of public health people and public health approaches. So I was going to kind of talk about that, which I will, but given what has happened in the past couple of months, I guess my thoughts are kind of consumed with what's happening under Covid-19. So this is a kind of re-tooled talk called: Disabled people and public health and pandemics, and offering some fairly scattered and unformed thoughts which I thought would be really useful just to share as a starting point really and to provoke some discussion on thoughts, and action, I suppose.

(Slide 2) So today I'm going to talk about, I mean slightly caricatured, but a couple of public health traditions which on the surface of them look quite different but when you think about how they treat/don't treat disabled people, asking some questions about 'actually, are they in their own different ways, equally ableist?' and then go on to think about, I guess, where are we...from the first month or two I've seen this playing out as it hits the UK – what can that tell us about public health approaches and what they mean for disabled people. So that's what I'm going to talk about.

(Slide 3) So one, I guess the most traditional approach to public health, is a very medical approach. And this is something I guess, that I was quite shocked to encounter when I started spending more time with people in public health because I realised how starting assumptions were completely different. So, on this medical view, health is the absence of illness, so it's nothing more than that and I think there's a real question in this approach as to whether health is considered to be the absence of impairment. I think there is a confusion between the two in this tradition of public health that can actually be quite fatal in its consequences with people. And this approach to public health really has an explicit utilitarian aim. Its aim is to maximise, what it considers to be able and healthy people, for the purposes of economic productivity. It seems part of its role to reduce the number of people who are a 'burden' on taxpayer/general public and in my view I think human rights are often secondary in this view to achieving those utilitarian aims.

(Slide 4) So some of the tools, which you all be more than familiar with I'm sure, that this approach uses: prenatal screening – for example, around people with Downs' Syndrome, which is termed 'primary prevention', so some of the newer prenatal screening tests, when they've been introduced, in some countries have reduced the birth

rate of people with Downs' Syndrome to virtually zero, but that is thought to be a public health 'good' on this point of view. There is a tendency to place the responsibility of health onto individuals. So you hear lots of talk about different lifestyle practises, so the response to that, in this view, has been behavioural interventions, which are, themselves, very ableist in their construction. So you quite often see, on Twitter, where I spend far too much of my time, there'll be a public health obesity conference somewhere and they'll proudly show off about how they've turned the lifts off to make everybody use the stairs, and the interventions are ableist in all sorts of different ways that this approach doesn't really consider at all. Then there's some technical stuff about the Quality-adjusted life years and the Disability-adjusted life years. These are used to determine which interventions are, supposedly, cost-effective, where basically, non-disabled people are making judgements about the quality of the life of disabled people, and particular impairments. That means, for an intervention to be effective, for a disabled person, it has to be cheaper than it would be for other people. And that's really important in all sorts of guidelines about considering drug use or the cost-effectiveness of different interventions too.

And organisations like Public Health England, one of their biggest outcome indicators which they trumpet is a disability-free life expectancy. Well if you're born with an impairment, then what on earth are you supposed to make of a nation that puts that as one of its principal goals.

(Slide 4) And, of course, this approach is fundamentally ableist through and through. It's clearly eugenic in its impact, even though the word eugenics isn't used, that's clearly the effect of it. And if disabled people are assumed from the start to be a burden, if you frame things in that way, then public health, as I put here I suppose, doesn't consider disabled people to be part of the public in public health. So disabled people are 'other' or ignored or not considered and it also doesn't consider that disabled people can be the tax-payers. As I mentioned, the effect of Quality of life method is to judge disabled peoples lives as quantitatively less worth living and that does work through in various decisions that are made. Routinely, disabled people are completely excluded from public health decision making and research, and there's a project that I was involved with, led by Carl Atkin and Maria Bird s a few years ago and they're disabled people and why quite rightly people are distrustful of mainstream public health approaches and inclusion within those decision making processes. As I mentioned, in all sorts of ways, the design of behavioural interventions exclude disabled people. That's both, in terms of, what they're designed to do, in terms of how they operate, but also in terms of where they operate. So those behavioural interventions are not designed to include where disabled people are more likely to be or not. An obvious example is school-based public health interventions, which rarely consider that they should be operating in special schools. And this approach only focuses on outcomes where many people are at a disadvantage. It ignores the sort of outcomes such as well-being which is relevant to anyone. So a very common measure used is called EQ5D which has various variants and this is a 5 question item that's supposed to determine the quality of life which is used in all sort of research, it's used in all sorts of ways of judging how

cost-effective things are. And questions in that, which are actually supposed to be about health, are actually about how mobile people are and so there's a disadvantage right from the start. So that's one tradition, I think one that we've probably all encountered in some form or another.

(Slide 5) There is another public health tradition which I think sees itself, quite often, as competing with or in conflict with, that kind of, medical model, and this is a Social Model of health inequities. This starts from a very different view of what health is. So this World Health, in 1946, the definition of health, states "health is a state of physical, mental and social well-being..." and here's the kicker you can see, which is why people have some issues with it, "...and not merely the absence of disease or infirmity" (as it was put). So clearly there's potential there, for it to be a much more positive and useful way of framing what health is and what we should be working towards, but again, that sort of kicker of 'infirmity' at the end, suggests that it's sort of chalice based. And this is the kind of microeconomics based, I guess, the social determinants of health is what public health needs to focus on to eliminate health inequities. So what Michael Marmot talks about is the causes of the causes. So, if we want to reduce people smoking then maybe as well as looking at smoking, you also look at what factors cause people to take up smoking in the first place and to keep smoking.

(Slide 6) So this is the sign designed by Margaret Whitehead and her colleague, Dahlgren, as this: so this is moving from an idea of differences in health or disparities in health, which the US quite often talks about, to health inequities. So, they say "three distinguishing feature, when combined, turn mere variations or differences in health into a social inequity in health". That is that these differences are systematic, and again, as part of the work I was doing with public health for nearly 10 years, we were demonstrating that the differences in health between somebody with learning disabilities and people without learning disabilities were definitely systematic and pervasive. Secondly, that those health differences are socially produced and therefore you can modify them. So what came up a lot in the literature around people with learning disabilities is that there is this difference in health and people start to look for reasons to do with the person's disability. And actually, we did quite a lot of research around, when you take into account, differences in socio-economic circumstances, for example, poverty, discrimination...then in differences between people with learning disabilities and people without learning disabilities in terms of health, can reduce them and also sometimes disappear. So those sort of social conditions is really important actors. So those differences are not an inevitable function of a person's impairment, it is about the social conditions in which people are living. If their condition, which is really crucial that they talk about is, society has to see those differences as unfair, and I must admit, in term of our work that we were doing, we got nowhere near that point. I don't think society at as a whole, if they really know those differences even exist, really considered that they are sufficiently unfair to be motivated to take the kind of action that would be required.

(Slide 7) So, I guess, part of me, and this was pre-COVID, I guess, was thinking that this approach, this kind of social model, despite its wrinkles, shall we say, could be more promising for disabled people. A social model of health is potentially more inclusive for everyone because it focuses on factors such as well-being which are relevant to everyone and doesn't disadvantage any group. It does recognise the importance of social and economic conditions and fiscal environment, in a way that the medical approach to public health doesn't do. And, again, given the sort of social and economic disadvantages many disabled people experience. I think that's really important. Another interesting thing is that the policy prescriptions about what to do about these situations are also social and economic not individualist. So I hear prime people talking, quite explicitly, about poverty and reduction strategies about issues around housing, about issues around transport, and it goes on. And in most ways, this approach recognises the intersectionality, so they recognise that there are issues around age, for example, around gender, around sexuality, that go with differences in socio-economic circumstances. So in some ways I guess that my view is, was/is, I don't know, that it might be a more promising approach for thinking about disabled people, I guess.

(Slide 8) But the more I think about it, the more I guess I've spent time with people who are working in those social model traditions, I still think there are some real problems. One is that disability is completely invisible within the way that that tradition is working. So disability is not considered in factor in analysis' of intersectionality, at all...disability is just completely ignored in any analysis' which I find striking and I can't really get good answers from people as to why that might be. The kind of policy and practise prescriptions that are produced are based on an assumption of what the general population is and rarely consider disabled people or what those issues might need in terms of how those policies and practise prescriptions will apply or not. Another thing that really surprised me is that public health interventions and approaches, even within this social model, are very rarely evaluated for their inclusion of or impact on disabled people. I was actually quite speechless at this and the way that people kind of shrugged their shoulders. But surely a massively fundamental issue, if you're looking to tackle fundamental inequities in our society, the experience of disabled people, should be absolutely crucial in that. And the final point for me, I think this approach sometimes strays into or sometimes gets into talking about stigma, for example, but it downplays or ignores the issue of disability discrimination as a driver of inequities in health. And in research that I and my colleagues have been doing over the past however long, this comes out as a really important factor, in terms of explaining inequities in health between disabled people and other people.

(Slide 9) And there are a couple of, sort of, trendy public health approaches with I want to kind of mention quickly, and again, thinking about what their impact might be or how they might apply, or not! One is, there is a lot of talk about 'place-based' public health approaches, so you hear a kind of asset-based community development, you hear about place-based approaches, social prescribing sort of leans on this kind of approach and the idea really is that you consider people in their neighbourhood and you grant some measure of control or money or budget or some combination of those things so

that people focus on the things that they think are important rather than other things determined from on-high! Now that, in some ways, that's really exciting, but I think there are real limitations in how this has been conceptualised and used, or not, with disabled people. One is that community is conceived, almost always, as a geographical neighbourhood, a physical place based on indices of how deprived places are and there's no consideration at all, when these things are up and running, of who these communities might be excluding, who these communities might be inaccessible to or just missing out in any evaluations of these kinds of approaches, again have completely excluded any consideration for disability. Another trendy approach at the moment is 'inclusive growth'; so this is kind of the local economic model and quite often people talk about, the idea is that in a town or city or place (a town or city usually); I guess the locality had anchor institutions in place. It might be the local authority, it might be NHS, it might be a university, that all are anchored in institutions. They all have fundamental purchasing power and fundamental powers in which they can shape their local area, and the basic idea is, rather than it all going to institutions outsourcing everything – so, sending the money out of the area, often to large corporations where profits are salted away somewhere else – basically you try and use that money locally, you try and build things that are needed locally. So it keeps the money local, it grows peoples skills, it hopefully improves employment and it includes more people in that local economic growth. And again, I think that is a potentially really interesting and exciting model, particularly for when you think about social care, for example, which is dominated, in some ways, by very large companies running very large homes but, in terms of how it's operated so far, I haven't seen anything about disabled people as contributors or part of that inclusive growth. Disabled people may sometimes be seen as the objects of that growth is applied towards rather than personally contributing to that. And also, so far from what I've seen, social care has been completely excluded from that sort of inclusive growth approaches, and again, if I was a local councillor, I would see that as the place to start with this kind of approach.

(Slide 10) So that's kind of what I was going to talk about before and then these sort unformed thoughts, I guess, as I've been trying to follow what's going on in this pandemic and just trying to do a set of really simplistic tables about some public health approaches and what we're seeing, in terms of Covid-19. So there's a few of these, and these are kind of points for discussion, I think, rather than anything else. So the first thing is that the public approach is utilitarian and human rights are secondary. We're seeing that gradual, well I don't know how gradual it is, but the dissolution of human rights, particularly those involving disabled people. So, local authority Care Act 'easements' (again, interesting choice of word) and in terms of patient health and care plans for children, but now the councils just have to make reasonable endeavours, rather than actually be responsible for producing things. Also, I think we're seeing the utilitarian approach, I mean herd immunity I think is their front and centre in terms of reducing the "burden" on the public purse. So we're seeing more and more now, calls to stop lock-down for the sake of the economy, despite the likely catastrophic impact of this on some groups of people. And at the moment the only policy response I've seen to any of these that are people-led, it's likely to have a catastrophic effect on

shielding, which again, is a revealing term. Basically, there is no strategy or support for people in this position or people in other positions who need support, basically beyond food parcels.

(Slide 11) And I think there's plenty of evidence of this kind of utilitarian approach having eugenic impacts on disabled people. So we've seen blanket DNR's placed on disabled people's medical records without any consultation at all or without any due process. We've also seen, kind of, blanket letters being posted from GP's to people. I guess there's the issue of rapid guidelines, on who gets intensive care, in terms of the use of the clinical frailty scale, which is basically as it applies, basically means that many groups of disabled people would count as frail and that would mean that they're less likely to get various forms of intensive care. The whole idea about protecting the NHS, and again, we can have a big discussion about this, but it's revealing to me that that comes ahead of 'save lives'. The policy and quite bullying-like enforced practise of moving people with Covid-19 symptoms, who've been tested positive for Covid-19, I think...maybe not always, but being moved into care homes to protect the NHS, without testing, without any consideration of where they're moving to or without any consideration of what will happen to anyone else living in that care home. There was an issue which was challenged, again, legally, around exercise guidance, so again, this is once a day and had to be legally challenged in terms of; being out of the house is actually really important for some people, especially in terms of mental health and well-being so that wasn't there in the first place, here had to be a legal challenge. And there's been suspensions of all sorts of NHS services which apply to disabled people. So LeDeR reviews, that's the learning from deaths reviews of people with learning disabilities has been suspended, wheelchair and postural support were downgraded, in terms of whether it should be applied or not. Annual health checks for people with learning disabilities, again, have been suspended and there are probably many other too which I don't know about. And there's really been a fundamental lack of interest, I think, in supporting disabled people to stay safe and supporting people who are supporting disabled people to stay safe – very little consideration, very little practical and financial support.

(Slide 12) Again, I think there's this issue of the medical model of health conflating impairment disability and illness, so phrases like 'underlying health conditions' has been quite sinister really in their application. The whole issue of 'shielding', so who should be shielded. So it's defined in terms a set of specific medical conditions, and that set of specific medical conditions; 1) doesn't include some things that are very important for many disabled people such as dysphasia, which is a real issue in terms of pneumonia. It's also linked to people from a medical professional, so it seems to be much more difficult to argue your way onto that list even if you have multiple and complicated health conditions. And also that list of medical conditions then determines eligibility for various different kinds of support, so the NHS food parcels, which on Twitter you see pictures of scarily large onions or tins of Spam, but it's a set of medical conditions which determines the eligibility of support which is nothing to do with the medical condition. And the response so far has really only been focused on PPE, testing,

shielding for people, etc. There has been no practising of policy consideration, really, for what issues of isolation are doing to people – given that CQC is no longer inspecting, what about people who are living in closed service environments, what is this doing to peoples well-being?

(Slide 13) I think what we've really seen is that disabled people really are not in the 'public health' during this pandemic. Disabled people are invisible, in term of, policy and practise. Social care, to start with, was roundly ignored or being used as a kind of handmaiden to the NHS and now social care is currently being equated with care homes for older people, no consideration of other groups of disabled people living in lots of other circumstances. The National Care homes federation keeps using this term 'ring of steel'; what we need to do with people in care homes is protect them with this ring of steel. If I was in the middle of a ring of steel, that would terrify me, I would not feel safe and protected at all and I haven't seen any consideration at all to what older people in care homes or what disabled people actually want, in terms of their lives moving forwards. The approach, really, hasn't been about where many disabled people live, what many peoples requirements for support are and very little on the contributions people are making. So the ONS has done an interesting online survey of disabled people and non-disabled people, arguing that people, both groups are equally likely to say that they were getting support from locals and they were supporting locals as well, but that doesn't make any kind of media narrative. And, again, an obvious example is; no sign language interpretation in the daily media briefings which is just...I don't know what that says!

(Slide 14) Also, for me, I guess because I'm a bit of a data nerd, is that disability has not been considered as an aspect of intersectionality and information about disable people is just completely absent from any kind of public policy or practise discourse. So now we have public analysis' of all sorts of things related to Covid-19 – deaths, for example, age, sex, areas of deprivation, location (in terms of postcodes), care homes, local authorities. I haven't seen anything public yet on deaths in different groups of disabled people or people who are using supported living or home care or people in mental health in-patient units. there's also an issue, you know, with endless, big online surveys now being constructed about people's experience of Covid-19 and so far, I think there's one in Greater Manchester which is for disabled people specifically, but beyond that, I haven't seen any examples where there have been surveys made accessible to different groups of disabled people.

(Slide 15) And these approaches really ignore disability discrimination as a factor driving health inequities, so there's no strategy for disabled people which some countries have, Australia and Canada, for example, do and there's no organised group of disabled people contributing to policy or strategy around this. You see heartwarming stories of 'miracle survival', of people with learning disabilities are examples of this; sometimes they don't look so heart-warming to me, so when you read about the young guy with Downs' Syndrome who basically ended up at an end of life care ward in a general hospital and then survived, I don't find that quite as heart-warming as the story

was trying to persuade me to do, and again, this phrase ‘underlying health conditions’ I think is pernicious. And I think there’s a real issue that care homes are being presented as kind of heroes and victims simultaneously, so there’s no discussion of the broader economics, I guess, of care homes and some of the large care home chains – there’s no discussion of profits, for example, or whether the size of the care homes that people are in is a really bad idea in terms of keeping people safe in a pandemic – those kinds of issues.

(Slide 16) So, ill-formed thoughts from the middle, or the start, of this pandemic...I don’t know where we are in this. I suspect we’re nearer the start. If it ever went away (I’m not sure that it did), medical public health seems to be back with a vengeance. Government and health organisations seem to not be seeking any strategic and or active contribution from disabled people. They seem to not be considering disabled people in their thinking. So the medics come out with guidance saying something and then people are left scrambling trying to interpret what that means for various groups of disabled people. With the lack of publication of information which they clearly have and have had for some time, it really does feel like the government are trying to cover their tracks, in terms of the impact of how this is working out for disabled people and things like Care Act ‘easements’ really are created to undermine the basis for a legal challenge to some of the things that the government are doing or not doing. So my final conclusion isn’t a conclusion, it’s a question for us to talk about, I think, which is ‘what to do’? Thank you very much.

(Slide 17) That’s where you can get in touch with me in various ways or read my ramblings. So that’s it, Miro.

Griffiths: Brilliant, thank you, Chris. That was much appreciated.