University of Oxford Disability Lecture 6 June 2022

Dr Amy Kavanagh

Hands Off: Navigating unwanted touch, consent and disability

Transcript

Introducing the speaker

Sarah Stephenson-Hunter:

Good evening, everybody. My name is Sarah Stephenson-Hunter, she/her. I am the Staff Disability Advisor here in the University of Oxford Equality and Diversity Unit. It's my absolute pleasure to invite you all to this lecture. We have a fantastic lecture lined up. We have a fantastic speaker.

And just a bit of housekeeping for you: obviously we're in the wonderful world of Zoom, so hopefully most of you are familiar with it by now. If you're not and you have any technical questions, you should be able to enable the Q&A and ask our team to answer those questions. Also, we do have live captioning available throughout the session. Hopefully you are aware how to access that. If not, if you go on to the Captions box on your Zoom panel, you should be able to access it that way. Our speaker will be sharing slides, but they will talk through their slides, and I believe that is everything.

So in a moment I'll hand over to our Vice Chancellor, who will introduce the speaker. Then Amy Kavanagh, Dr Amy Kavanagh will speak. And we will have Q&A. So hopefully that's everything.

The session is being recorded, so if you would like access to it afterwards, if you're obviously here and you're registered, we will be sending emails out to people to say where you can access it. If not, look out for social media and it will be on there as well.

So yes, our speaker this evening is Dr Amy Kavanagh. I'm really delighted that we have Amy with us. I have been following Amy for quite a while. She goes under the Twitter name of @BlondeHistorian. She's a campaigner, a speaker, an advocate. She does work around obviously disability, accessibility. She's also a video gamer. She's won many awards, been on the likes of -- oh, what's it called, Steph's Place on Channel 4. She's done many, many, many great things, and we're so looking forward to having her speak this evening on a subject that I think is really important and really vital. And so I will hand over to you now, Amy. Thank you.

Lecture

Amy Kavanagh:

Thank you very much, Sarah. It's a real delight to be here today. I'm just going to share my screen. And I'll do a little audio description of myself. I am a white blonde woman. I have got dark-framed glasses on, and I'm sat in my office at home wearing a rather fabulous pink headset, and behind me there are lots of books, and all sorts of interesting odds and ends on my shelves, because this is also where I do my video gaming from.

So this lecture today is going to be an exploration of the disabled experience of unwanted touch, forced help and consent. I'm drawing on my lived experience as a blind activist, but I am also grateful to the hundreds of disabled people who have shared their stories, reflections and thoughts about their own experiences with me over the years.

This lecture draws on the themes and consistent tropes surrounding unwanted touch and forced help. In doing so, I'd hope to draw some parallels between some of the wider challenges of also navigating cultural, social and economic disableism.

[shows slide] So a little bit about me There I am on the left, standing rather proudly with Guide Dog Ava on my high street. Guide Dog Ava is with us today. I will just briefly change my camera, see if she's in view.

There she is. She's probably having a lovely sleep right now. She's heard a lot of this before. She's heard me practising it, so she'll sleep the whole way through, I should imagine.

Hopefully change back to me. There I am.

So I was born with a condition called ocular albinism. I am registered severely sight impaired or blind, and I use either a long white cane or Guide Dog Ava to aid my mobility.

I'm an activist, freelancer and content creator, and as Sarah said, I'm interested in all sorts of different issues, from public transport, disabled women's rights, video game accessibility, the built environment, and digital inclusion.

And most of all for me it's really important that today is a trauma-informed space, so this lecture will include challenging material. I will be discussing and sharing examples of disableist violence, ableist language, discussions around the police and hate crime, as well as sexual assault. If you find yourself activated by any of this content, give yourself the space, support and time that you need. And if you need any supports during this lecture, I really encourage you to access them now, whether it's stim toys, aromatherapy, journalling, snacks, whatever best supports you to participate. And please listen to your bodymind. That's really important, and turning off is a valid choice. I will not be offended, and you can come back in your own time. There's going to be a podcast. There will be a transcript available.

Do be mindful of what you share in the Q&A / chat function. Just make sure that it remains as an empowering a space as possible. And if you need support afterwards, I have made a note of some services that I think will be broadcast now. I particularly recommend The Survivors Trust, which has a live chat and a free phone line, which is open until 8 p.m. this evening.

So in my mum's words, who I think might be watching, how did I end up talking about being groped on Radio 4 all the time? So despite being born with my visual impairment, I rejected my blindness and my disabled identity until about five or six years ago. Twenty-something Amy would be absolutely horrified by me doing this. I left what was an extremely toxic academic career, and I started to explore disability activism and found the support of an amazing online community. And that meant that I built confidence in my disabled identity, and that included embracing the support of a mobility aid, my white cane.

And as I did that, there was a fundamental disconnect between my joy in my disabled self and the reactions of non-disabled people. Now someone born disabled, I have always known the structural barriers and inequalities of disableism, but suddenly being visibly disabled brought me a whole new host of experiences and confrontations. And as I learned to use my new white cane in 2017-18, I started experiencing what I call 'grabbing'. And this varied from being dragged across roads, pushed into seats, even shoved onto trains I didn't want to get on. And I was horrified by the amount of unwanted touch I was experiencing.

And as I started talking about it online, I realised I wasn't alone, and that this was something that a lot of disabled people experienced. And therefore, the #JustAskDon'tGrab campaign was born, and I have a few examples of people who have shared their experiences here, some using the hashtag, others that have been linked to the hashtag.

Vicky says:

> Was getting off a bus and a random guy thought he would help by grabbing my crutches, causing me to almost fall. That was fun.

Campko:

> I think this belongs in #JustAskDontGrab. Some guy tried to help me put my jacket on, I swerved away and said ‘Please don't touch me.’ He got red in the face and yelled at me, ‘What, do you think I'm some rapist?! Don't flatter yourself!’, and stormed off.
>
> That's that one there.

Waiting for Doggo:

(There's a blind emoji here and then kind of a shocked face emoji.)

> This morning walked down a busy road. Someone grabs my rucksack from behind. I pull away and shout for them to get off my bag. I am then met with a torrent of abuse from the bag grabber and another passerby, whose justification was that she was trying to help me.

(And you might note that that one happened three days ago.)

This is from Gregory:

> Stranger: ‘Here. Let me take over.’ (Starts pushing my wheelchair.)
>
> Me: ‘Thanks, I got it.’
>
> Stranger: ‘I insist.’ (Keeps pushing.)
>
> Me: ‘No. I insist. Please take your hands off my chair.’
>
> Stranger: ‘You don't have to be rude.’
>
> Asking someone to not grab my wheelchair is not rudeness.

And this from RieRie:

> Today my basket was lifted from my lap and tugged out of my hands by a member of staff who insisted they were helping me. I was at a self-service and not indicated I needed help. What they were going to do would have made it harder for me to use the checkout! #JustAskDontGrab - simple!'

The hashtag functions both as a space for disabled people to share their stories, like the ones here, but also as guidance for non-disabled people to learn about the impact of unwanted touch. The hashtag has gone viral multiple times and been covered in national and international media.

[shows slide] On this slide I have a selection of different headlines, different publications, ‘Just Ask Don't Grab’, ‘Blind Activist Wants to Change the Law’, spikes, harassment, they just layer on top of each other, because this is an issue that disabled people talk about a lot.

Too often when someone shares an incident online, maybe for the first time, perhaps after the first use of a mobility aid, I've witnessed an often really painful moment where someone in the community says, 'Actually, this is an everyday part of being disabled'. And it absolutely isn't limited to those who use mobility aids. It impacts any disabled person who appears to be navigating the world differently. And it's important that non-disabled people understand that the incidents are unrelenting. I've experienced on one occasion, I counted, I was like, 'Right, I'm going to count today'. This is pre-pandemic. In an hour I went from my home, I got on the bus, I went to a shop, caught the bus home. In that hour I experienced unwanted touch 16 times. These incidents have a real impact on your confidence, on your willingness to go out, and your independence.

And as some of the headlines I shared demonstrated, this is an issue which particularly affects disabled women. In the three years ending March 2018, disabled women were almost twice as likely to have experienced any sexual assault in the last year, at 5.7%, than non-disabled women at 3%. And significantly, disabled women were over five times more likely to have experienced sexual assault in the last year, 5.7%, than disabled men, 1.1%.

These statistics are painful and they are shocking, but they are important. Too often when I talk about Just Ask Don't Grab, I'm told that the people who push me off a bus or drag me into traffic are trying to be nice or they have good intentions. And whilst this lecture seeks to explore the goodness of those intentions, it is essential to understand that a significant proportion of the unwanted touch that disabled people experience is violent, is aggressive, and is frightening.

The campaign has also generated ongoing research into the experiences of non-consensual touching. Dr Hannah Mason-Bish, a Senior Lecturer in Criminology and Sociology at the University of Sussex, has collated over 70 stories from disabled women and non-binary people as part of the Private Places, Public Spaces project. This project is ongoing. We are looking at what more research we can do, because it is a woefully under-researched subject, even though we have statistics like this. Academic research into experiences of unwanted touch are still overtly limited to care home settings or medical settings. There is really insufficient research into the wider experience of this issue. In the very powerful words of one of the contributors to this project – I think this really sums up a lot of what I'm going to be talking about today –

> ‘I feel like I am public property having such a visible disability, and people's reactions, although well-intentioned at times, are just a perception of what they think having a disability means – needing help all the time.’

I use the phrase 'unwanted touch' because it embraces the spectrum of non-consensual physical interactions. This includes the ostensibly 'helpful' attempts at physically moving or aiding a disabled person, as well as touching mobility aids, like a wheelchair or assistance dog, but also intentionally harmful touch, like physical or sexual assault.

Unwanted or unexpected physical touch can exacerbate impairment experiences, from people who are autistic to those experiencing chronic pain, the act of unwanted touch, even non-violent touch, can be distressing, can cause sensory overload, pain, or at the moment and still, concerns about infection for people who are immunocompromised.

In incidents of grabbing and unwanted touch, as we saw in the example shared earlier, there is frequently an absolute disregard of consent. Even saying 'No, this will hurt me' is ignored in favour of the perceived act of ‘good help’ by the non-disabled person.

I have found my own consent ignored so much that the word 'No' or 'Stop' has no effect. My technique now, and I mean, feel free to try it out yourself, I squawk like a bird. I just make a loud weird noise, and I find that people are more likely to let go of me if I make a loud strange noise than if I say 'Please stop touching me'.

And this entitlement to touch and the perceived benefit and goodness of touch has a complex and painful history for disabled people. Historically the State, the Church, and medical institutions have been entitled to disabled bodies. Laws were enacted and institutions were created to control, discipline and fix disabled bodies, the ultimate goal almost always being to treat or fix the impairment. [shows slide] And in the absence of an appropriate cure, institutionalisation enabled control and regulation of disabled bodies and minds: bodies and minds like those of William Norris who is sketched here in Bethlehem Hospital in the early 19th century. William is shown in a cell lying on a cot with straw matting. They are wearing some kind of long nightdress, and they are chained to the wall by a harness that is attached to both their neck and arms, and their arms are restricted and pinned to their sides. The urge to fix and treat the impairment and correct the disabled body is often referred to as the Medical Model.

[shows slide] And frankly I couldn't find a more powerful image showing the Medical Model than this one. There is a real urge to fix here. Again, this is a 19th-century image later on, it's a photograph, and it shows a tripod that has been erected with a winch on it, and the disabled person is being held up by this winch mechanism as three men around them affix plaster of Paris to their torso in an effect to correct their spinal curvature.

The Medical Model, in the words of French and Swain,

> ‘is a series of disciplinary practices aiming towards creating docile disabled bodies, bodies who are expected to adjust to their impairments and comply with the prescribed regimen of rehabilitative treatment administered by medical professionals’

and this is something many disabled people still experience today. People will frequently share experiences of medical ableism, where consent to procedures is completely ignored by doctors in favour of the alleged good of the treatment.

It's also really important to understand the institutionalisation and discipline of disabled bodies is not a thing of the past. In the UK there are currently over 2,000 people with learning disabilities and/or autism detained in in-patient hospitals. On average, the length of stay in these inappropriate and frequently reportedly violent settings is five and a half years. This includes several hundred children. Furthermore, disabled bodies are not just the property of doctors and institutions, but non-disabled public is still actively encouraged to consume and interact with disabled bodies.

[shows slide] Here I have an image of the Undateables programme, which is still produced, and endorses the idea that disabled people are available for consumption and entertainment. And unfortunately this is something we cannot even escape in death. [shows slide] Here I have an image of Charles Byrne, known as the 'Irish Giant', in the mid to late 18th century. Now Charles Byrne had a condition which meant he was 7'7" in height and was famous during that period of time. Now, Charles unfortunately had ill health towards the end of his life, and knew that he was going to die. And he also knew that the eminent scientist John Hunter wanted his body, and so Charles worked incredibly hard to plan, so that his body would be put in a lead coffin and that he would be buried at sea just off Margate, but Hunter foiled the plan, seized Charles's body, and experimented on it, displayed it... and it has sat in the Hunterian Museum from the 19th century until 2016, when the museum was closed. They are still debating whether or not they will continue to display Charles's skeleton when the Hunterian re-opens, even though he explicitly and expressly requested that his remains would not be displayed. And this is the legacy and impact of the Medical Model of disability: the steadfast belief that impairments need fixing, that an impairment means something is wrong with a body; it is a weakness in need of treatment and intervention, and that, therefore, non-disabled people are entitled to disabled bodies so that they can be fixed, observed, controlled and examined.

Fundamentally, many of the interactions involving unwanted touch and forced help result from these assumptions of incapacity. With disability and impairments continually framed as tragic, or an individual obstacle to overcome, the disabled body and mobility aids are frequently reduced to passive participants in society and the physical environment. There's a fundamental lack of trust that a disabled person can have autonomy or expertise or confidence in their bodymind and capacity. These are the strangers who yell at me in the street, demanding to know if I'm lost because they cannot possibly envisage an independent blind person. Our aids, like a white cane, an assistance dog or a wheelchair, instead of being recognised as tools of enablement and independence, are instead interpreted as symbols of incapacity. They become announcements of our alleged need for assistance instead of the support systems and mitigations that they actually provide.

And the conclusion is therefore that, instead of requiring non-disabled people to be allies in removing physical, sensory, cognitive, financial and communication barriers, that instead non-disabled people must assume a role as the intervention themselves.

We are constantly remonstrated with phrases like 'I was just trying to help' when we reject these interventions. And as a result, we're forced not only to navigate inaccessible environments, but the assumptions of non-disabled people as well. And although many of the actions of unwanted help do involve physical touch, there are other important areas to reflect on: the classic being opening a door for a wheelchair user, and this is a nice gesture, you know, opening a door, it's very polite to open doors for people, but it's often actively unhelpful because the non-disabled person assumes, you know, doors are a great and impassable barrier, and they take on the role of the door opener, usually only to create a barrier themselves, or what some of my wheelchair-using friends call 'the armpit-sniffing dance', where the arm is physical put across the door so that you can't actually get past the person because they are stood in the door trying to get you through the door, and if they'd just let you through the door yourself, you could use the flipping door.

Other examples for me include the drivers that try to wave me on at traffic. 'You can cross, love, it's all right.' And I can hear the motorbike coming around the corner. Or when people take bags, or food, or items of clothing, or other possessions away from disabled people to try and do a task for them. The example we had earlier of trying to put on your own jacket and someone deciding you can't do that for yourself.

And a key theme amongst these actions of unwanted or forced help are that they take decisions, independence and autonomy away from disabled people. They are actions without permission and without consent. It is frequently a case of a non-disabled person making a decision on behalf of a disabled person. And the assumption remains that they, as a person without impairments, without disability, are better equipped to function in the world and should act, instead of removing the obstacles or barriers which are currently preventing independence.

This belief that non-disabled people have a duty to help and assist disabled people is actively encouraged by what is called the Charity Model of disability, and the Charity Model draws on the Medical Model by framing non-disabled people as the saviours of disabled people. [shows slide] For me this is best represented by the infamous Chip the Crip collection boxes, and here we have a contemporary photo of a young child putting money in the tin for the Help Spastics campaign, and the collection box is in the shape of an infantilised little girl, and she's holding up the tin that says 'Please Help Spastics', and she has a leg brace on. These were very popular on high streets right up until the 1980s. Lots of people will remember these. Fundraising initiatives represent disability as a tragedy, something that can only be remedied by financial interventions and services, not from the state and not through the provision of rights, but through the actions of non-disabled publics.

And the sociologist A.J. Withers highlighted that children are often used as imagery for Charity Model fundraising efforts. Seriously, go Google the latest campaign from, you know, Scope, RNIB, Autistic Society, always using children; and Withers says that this is because the underlying message is that fundraising gives hope. And hope mostly of a cure or a remedy, and because if you show children, a cure could lead to them becoming productive workers, and children are innately more pitiable in this framing. And this message 'Disability is a tragedy that needs remedying' really spurred on the Direct Action Network in the 1990s, and [shows slide] here we have a photograph of the famous Block Telethon campaign, where many disabled people, wheelchair users are at protests with brightly coloured banners. And Piss on Pity was a challenge to the trauma porn representations of disability and the failure of society to be accessible for disabled people. And if you want to learn more, you can very much enjoy the representation of this event by watching ‘Then Barbara Met Alan’ on BBC iPlayer, and you might see me in the background doing some angry pointing.

But unfortunately, we're still subjected to mass fundraising events, often using disabled children as pity fodder for non-disabled people, thus resulting in a continued cultural framing of helping a passive, sad disabled person, being good, rather than encouraging people to question the inequalities that cause that disableism. Think about, if you want a classic example of it recently, think about something like the Children in Need Big Build, where they send Nick Knowles along to rebuild a house that's completely inaccessible for a family with a disabled child. And it's lovely. Lots of volunteers build the house and give their time and make them a lovely accessible home, but why is no one asking why they cannot have an accessible home in the first place? And why does that need to be televised? Why do we need the crying disabled child, they finally have a lift and some dignity. It's really troubling.

And this brings me on to kind of that next point, that crying, grateful, disabled child. Because many disabled people will be familiar, after rejecting an offer of help or challenging an unwanted touch, by the 'helper' gruffly responding, 'Well, I was only trying to help!' or 'You should be grateful!'. Because there's the expectation by a ‘helper’ that the disabled person will be grateful or will positively receive the interaction, regardless of any consent or any permission. And this is intimately tied to the assumption that help is automatically required, and that the non-disabled person is the one in the position of authority and expertise as the helper. And this problem stems from the societal framing of helping, and helping a disabled person, being an intrinsic good or a compassionate duty. And this is where we get the really tangled web of kind of good deeds and nice intentions, and it really annoys some people, because there is a simultaneous perception of a social contract. That's what I believe. There's the social contract that there is an obligation to be kind and to be good towards lesser disabled people, and therefore the reciprocal end of the social contract is the gratefulness that the disabled person must display.

And I'm not saying that helping a disabled person is always bad. You know, if you do it consensually and if someone genuinely needs some help and they accept an offer, that's fine. But the problem is that too often when a disabled person refuses help or rejects unwanted touching, it's like they are rejecting the non-disabled person's self-perception of goodness and kindness. We've made them feel bad about the good deed that they wanted to do. And then, actually, you'll find that regardless of any pain or distress or fear caused to a disabled person, it becomes the injured feelings of the non-disabled person that take priority. They were trying to be nice. You were rude. You've hurt their feelings ... as the bruises are forming on your arm.

And most importantly, if kind intentions are kind, they should not be conditional, and they should not be conditional upon compliance. And demanding compliance of disabled people extends beyond these acts of helpfulness. Expectations of compliance are frequently expressed in the entitlement to information about disabled people, and this ranges from the, 'Oh, what's wrong with you?' or 'Were you born like that?' from a taxi driver or an older person who sits down next to you on the train. It includes demanding evidence of disability, accusations of faking disability, and intrusive questions about bodily functions. And that latter one is very frequently a precursor to the help. There's an implication that you have to tell me how much you can see before I'll help you, or you have to prove to me that you can't use your legs before I'll help you. This questioning or commenting about a disability or impairment is also something utilised to refuse services or to deny access: the classics being demanding proof that you can use an accessible toilet or a parking spot. 'You don't look disabled.' 'What disability do you have?' 'You're not allowed that.' And this information is seen as a public right, a justification to give us permission to be present, and most importantly it is a protection. It is a protection against the potential deviance of disability. Because as people will always say, 'Well, those fakers could be using that parking spot'.

In November 2016, a UN enquiry found that the UK government, and specifically its austerity policies, had systemically violated disabled people's rights, and subsequent investigations have found over 17,000 sick and disabled people have died waiting for welfare and benefit support in the UK. And in the last fortnight alone, the government have announced a new crack team of investigators who, alongside a controversial algorithm, will be targeting disabled people claiming welfare support. These harmful government policies continue to be and were supported by a hostile media environment dedicated to outing disabled benefit scroungers. [shows slide] Here I have images of a collection of headlines from all different tabloids, and they constantly feed the public with lines about 'undeserving disabled fakers', 'scroungers', 'benefits cheats'. '75% of incapacity claimants are fit to work.' 'Mansions for scroungers.' 'Four million scrounging families.' And members of the public have been repeatedly encouraged, not just by the media, but by the government, to report on fake disability benefit claimants. If you put 'benefit fraud', the first thing that comes up is how to report somebody. They've made that really, really easy to do, but they've not made the PIP application easy, and I guess that says it all, doesn't it? In 2019, nine out of ten of these reports were found to be false after DWP investigated them. Nine out of ten.

And so we are then left with a society and a culture with their belief in the entitlement to the bodies and minds of disabled people, and this is a hangover from those very institutions of previous and current centuries, and it enables and supports a social power over disabled people giving permission to non-disabled people to question, to act, to examine, and to punish. And this expresses itself in acts of testing; demanding paperwork; the people that will intentionally walk in front of me in the streets just to check that I'm really blind; or the person who screams at you if you dare to move your foot in a wheelchair.

But this is an authority over disabled bodies and how we navigate spaces, and this is especially the case for particular groups of disabled people, especially those for whom – they have impairments that are seen as socially unacceptable, inappropriate, or unpalatable. For example, people who experience facial difference or limb difference find themselves particularly subject to controlling and violent behaviour by members of the public. Disableism ultimately expresses itself through hostility and acts of violence, where disabled people find themselves harassed and attacked. And sometimes this violence is even repackaged as entertainment, and as many individuals with dwarfism have bravely shared, frankly, they have experiences of being thrown, and then the incidents are filmed and circulated online.

And of course this is rarely endorsed by wider society – at least on the surface. There remains a kind of disableist culture which I call kind of ‘the permission to exist’, and it's the assumption that disabled people should be grateful for an accessible society. We should be thankful for the ramps and the welfare support. It's the people who say that they are going to pet my guide dog anyway because they donate to the charity. Or when you go to use the accessible toilet, somebody will announce, 'Oh, yes, you can go in. You're allowed in'. And the really sinister outcome is that if enough gratitude isn't expressed, or if this alleged benevolence becomes a burden, well then, that permission can be withdrawn.

[shows slide] The COVID-19 pandemic brought into sharp focus the inequalities faced by disabled people, and I have a very painful image here. In May 2021, Dominic Cummings released a photograph of the government plans in March 2020, what were they going to do to tackle the virus. And infamously this included a whiteboard, and scribbled on the whiteboard were the words 'who do we not save'. The latest figures still show that disabled people represent six out of ten deaths from COVID-19. And in their recent release, the Office of National Statistics stated, 'The analysis shows a continued elevated risk of COVID-19 mortality in disabled people compared with non-disabled people, which remains largely unchanged across the three waves of the pandemic'. And despite this continued risk, mask mandates have been dropped, support for the clinically vulnerable has been stopped, and social distancing is at an end. Throughout the pandemic, we have been told that 'it was only the most vulnerable at risk', that the deaths were mostly of people with 'underlying health conditions'. And during this pandemic, disabled people have found themselves on a knife edge between demonstrating that they are vulnerable enough to receive support, but not too vulnerable to just become a forgotten statistic. And since 2020, many disabled people have shared stories of members of the public telling them to go home, or that they shouldn't be out in public.

For many disabled people, that permission to navigate public spaces has been withdrawn, either by the lack of support to remain safe from the virus, or by increased feelings of hostility from the general public who aren't used to seeing them out and about so much.

In the extremely powerful words of Frances Ryan,

> ‘The truth is, disabled and older people were not ‘vulnerable’ to the virus simply because of their health or age: they were vulnerable because the government did not bother to keep them safe. What happened to our ‘most vulnerable’ during the pandemic was not some terrible tragedy. It was the all-too-predictable consequences of a system that decided the lives of disabled and older people mattered less than those of the rest.’

Because it's always a choice, and 'who do we not save' continues to be a choice every single day.

And as the pandemic has shown, too often getting the right support is contingent on demonstrating vulnerability, and at the same time expressing the right types of behaviour. And this pressure to disclose all your information about your body and its conditions and why you need support extends beyond health care and social support. Too often disabled people are demanded to live their trauma publicly in order to educate and raise awareness.

The news articles and social media videos exposing unwanted help are supposed to fill a gap left by education, and too frequently the demand is that we must educate kindly, that we must voice our distress with measured words and speak our truth without the sharp edges that express our exhaustion and rage.

In the *Metro* in April of this year Melissa Parker, an excellent journalist, framed it perfectly.

> ‘We're taught by broader society and by those around us to educate those who might harm us and to exercise understanding towards the people who abuse us, to see their humanity even as they flatten our own.’

This tone policing is another means of demanding civility and compliance from disabled people. We must ask nicely to be granted consent, bodily autonomy, or access, instead of voicing our rights or speaking our anger about their denial.

And for me, most painfully this is commonly expressed through lateral ableism – that is, disabled people policing other disabled people that they consider to threaten the politeness status quo. And the most common response I get from the blind community online is that by speaking out about unwanted touching I will stop anyone ever helping us again, that I am harming the community. And there is sometimes a really distressing belief from other disabled people that we have to tolerate the harmful or violent acts on the condition that sometimes we actively need assistance. The insistence by people within and without the community that we still need to ask nicely and educate kindly is troubling: because it perpetuates the idea that disabled people need to behave correctly and seek permission to be free from violence or to access equality. And most of all, let's face it, asking nicely isn't working. So instead of asking nicely, today I'm asking non-disabled people to examine their own actions and the disableist culture that has produced them. And I'm often asked, 'What are the solutions?’. And something that comes up as a common solution is hate crime and policing.

In 2020 to 2021 there were over 9,200 disability hate crimes reported to the police in England and Wales, with half of them classed as violent. And that means they involved assault or a weapon. I've even been anecdotally told that there are well-known repeat offenders who will specifically target disabled women on the transport network. And yet, just 1% of cases in 2020-2021 were referred to the Crown Prosecution Service or charged. 9,200 reports correlates to around 25 hate crime incidents per day. And yes, reporting hate crime helps with the statistics. It demonstrates the scale of the issue. And whenever I share or disclose an experience of unwanted touching or sexual assault or violence, everyone says, 'Oh, you should report it. You must report it.'. And really this demonstrates a complete ignorance of the inaccessibility and hostility of the criminal justice system, especially towards marginalised people. For many people, calling the police isn't safe. And we need to recognise that as a disabled community. As a white woman, I am in a relatively privileged position to report crime, but in the five years I've been reporting crimes, I haven't yet had a single prosecution. I've had CCTV. I've had ten minutes of filmed footage. I've had witnesses. I've had it all, and cases just get dropped again and again and again.

The first time I ever reported a hate crime and a sexual assault as a disabled person was 2018. I was walking home through Kings Cross, and I was in the pedestrian tunnel in the train station and a man came up to me. He kept saying he wanted to guide me, and he kept kind of trying to bother me. And I said, ‘No, no, I'm fine’, and eventually he started grabbing me. He was touching my breasts. He was assaulting me, and I managed to get him off me, and I called the police, and the British Transport Police said that because I'm blind I must have been confused, that there's a lot of homeless people active in that area and it was probably just somebody wanting some money. There's CCTV in that tunnel and they didn't even check it. And it's not just me. You know, studies have shown that the police are ill equipped to support disabled victims of crime. That is despite the disproportionate rate at which we experience it. Reporting is traumatic, time consuming, hostile, inaccessible, and ultimately fruitless for many disabled people, so unless you are prepared to support someone through this complex and often painful process, don't tell someone they have a duty to report or to 'just report it'.

Instead, one of the most powerful things you can do as an ally is to be an active bystander. And these techniques were developed by marginalised people, initially to deal with incidents of racism and xenophobia. It's really important to understand that bystander intervention doesn't mean riding in on a white horse. It is about taking steps to empower and support someone experiencing harassment or violence. And these are the five Ds of bystander intervention.

- So first, **distraction**. This is an opportunity to distract or derail the incident. It's probably the one I recommend the most. Focus on the person experiencing the harassment. Drop money. Sprinkle change everywhere. Ask the person experiencing the harassment the time or where the nearest bus stop is, or if they have a tissue. Because it shows the person experiencing harassment that you're there. You're there for them. You see it. It also shows the harasser that you see it. It's also a fantastic way to get someone away from a harasser, if the situation is appropriate. And I go, like, full bumbling blind lady on this. I, like, dial into those ableist assumptions and I'm like, ‘Oh I’m, oh I'm so lost. Can I – oh, could you possibly help me find my way?’. Get them in a place where you can get them away from that experience.
- **Delegate**. This is about involving a third party. This could be another bystander. This could be a member of staff. This is about 'I don't feel equipped to deal with this on my own. I want to use these other techniques but I need someone with me'. Don't call the police without the permission of the person being harassed. Like I said, it's not always safe for that person. Really good example of this I had someone was following me around the supermarket, petting Ava, they wouldn't leave her alone, and somebody went and told a member of staff, and the member of staff came over, intervened and got the person to leave me alone.
- **Document**. Make notes about what is happening. If you feel safe to do so, you can film or you can record audio. Even just noting the time, the location, a description of the harasser, all of these can be powerful tools. But filming is a precarious act. It can make a harasser feel seen and make them stop doing what they’re doing, or it can

hella ramp up that aggression. Afterwards ask the person who was harassed what they want you to do with the film. Do they want a copy? Do they want you to destroy it? Do not post it online without permission, and it feels really obvious to say that, but how many viral 'racist tirade man on the tube' videos have you seen on the Internet?

- **Direct**. This is the confrontational approach. I'm not going to lie. It's one of my favourites, but that's the kind of person I am. It involves challenging the harasser. Now, it does not have to be aggressive. It doesn't have to be violent. I actively encourage you not to be violent. You can simply name the actions. That can be very powerful. Stating out loud that you are witnessing it. ‘I see you being hateful.’ ‘You are harassing that person.’ Of course always assess your safety to do this.
- And **delay**, because you know what, sometimes we don't feel able to act, and that's okay. And if you feel unable to act, one of the most supportive things you can do is check in with the person afterwards. Do they want you to be a witness? Do they want a cup of tea? Are they okay? This simple act can be transformative for someone who's just experienced violence or harassment because it says 'I saw you, that wasn't okay, and I am here for you’. Always take the lead from the person being harassed. It's about supporting them in the way that they want.

I also recommend taking online bystander intervention techniques on-board. I recommend Glitch. They have a website. I often link to it online. They have really great online bystander intervention techniques which draw on these – because often when disabled people will share a story online of harassment, they then face the trauma of being challenged or doubted or abused upholding the behaviour or the actions of the harasser. Aka, 'They were being nice, you're being rude, you should be grateful', so on.

So in conclusion, I wish there was an easy solution. I wish I could wave a magic wand and say this is the one thing that will fix all of this. And today hopefully, you know, 100 people will take away a greater understanding of this issue, and I want you to talk about it and I want you to uplift the disabled voices who are speaking about it. Have conversations about this issue. Talk about it with your colleagues, with your kids, with people who you are sat next to on the bus. Tell them about Just Ask Don't Grab, and model consensual best practice of offering assistance. It's easy: Introduce yourself. Offer the assistance. Listen to the answer, do the helping if they want help, and say good-bye.

I hope some of you will become active bystanders and challenge the status quo, but fundamentally I believe that we need a radical shift in cultural understandings and representations of people and disability. We need education. We need access. We need disability rights. We need Nothing About Us Without Us.

But most of all, and this is the headline: help is not helpful if it is not consensual. Deciding when and how to help a disabled person, without their permission or respecting their needs, is not helpful or kind or nice.

And now I'm speaking to disabled people. We have a right to decide who touches us and when. You don't have to tolerate it or accept it when someone violates your boundaries or ignores your bodily autonomy. This doesn't have to be part of the experience of being disabled. We do not need permission to exist independently in public places, and we don't have to accept help that we don't want.

Thank you very much.

[shows slide] And those are my details if you want to get in contact.

Q&A session

Catherine Walter:

Lovely. Thank you so much, Amy. For the audience, I'm Catherine Walter. I am the Chair of the University's Disability Advisory Group, and we are just absolutely delighted to have Amy here today. I will leave more of that to my colleague later. My job is to try to get as many varied and interesting questions from those that were submitted to Amy to get her responses. So we may not be able to get them all in, but I'll try to give you a good mix to give you an idea of some of the reactions. So here's one.

> ‘Fantastic, thought-provoking talk. Much to go and think about. Thank you. In my non-University role, I work with children with autism or learning disability. Their parents are often mortified because their children go up to people and ask them questions such as 'What's wrong with you?’ ‘What happened to your legs?'. What is your experience of young or disabled children asking personal questions? What can I say to the mortified parents?’

Amy Kavanagh:

I mean, this is me speaking for myself, but from reactions I've had online I think quite a few disabled people feel similarly, in that children are going to ask questions, and they are learning about the world, and they are often asking from a place of curiosity and desire to learn. And I personally find it very charming and – absolutely happy to do that little bit of education, and mostly because children are coming from a place where they are not... they haven't yet absorbed that ableism, right? My favourite being there was a young child... I live in quite a middle class area in London, and I live near a primary school, so I get a lot of young children kind of making comments or asking questions. And I was walking along the street with my white cane, and a little voice pops up and says, you know, 'Mummy, why does that lady have a stick?'. And I could feel the energy, like this parent is, like, ready for this moment. They'd thought about it. They were going to answer it in the best way possible, and they went into this really great, like, age-appropriate description of 'This lady's eyes don't work, and the stick helps her move around'. They were like nailing it. And then the child just went, 'Okay. Why are there brown leaves on the floor?'. And, like, that question was the same scale for them. And I think evidently when there is also, you know, a cognitive need there, I don't think people should be mortified. I think hopefully disabled people are going to be the most compassionate with other disabled people, especially young people.

And I think it's about if you are a parent, like that parent I encountered, it's about trying to prepare for those conversations. And it's about thinking 'Have I exposed my child to enough representations of disability that they don't feel the urge to ask that question of a stranger?'. You know, 'Are there disabled characters in the books that we read together, or in the programmes that we watch? And have we had conversations about it?’. And there are lots of good examples of accessible resources about that as well, and creating social stories and sensory stories about disability. And quite frankly, as a disabled child, I wish I had met more disabled people, because I didn't. And one of the greatest benefits for disabled children is peer support, both from their own age group, but also from people who experience their disability as an adult. So I would really recommend, if possible, encouraging productive and informative and supportive environments where young people can explore those questions together with disabled adults.

Catherine Walter:

Okay, thank you. Okay, here's a very different question.

> ‘Hi, Amy. This is absolutely superb, and I love that you tell it as it is. I am so tired of having to be polite and protect other people's feelings.’

Amy Kavanagh:

Yeah.

Catherine Walter:

> ‘How do you manage all the anger? And how do you stop yourself from collapsing inwards? How do you stop yourself feeling like you are drowning and alone? Thank you so much for speaking up. I am just sorry that you have to.’

Amy Kavanagh:

Gosh, that's a powerful question. And you're right. It is really hard. For me personally, I do this. This helps me. It's not easy. Talking about it publicly does help. Dealing with the backlash is not so nice. Dealing with the trolling is not so nice, especially when it comes from other disabled people. I'm also in the very privileged position of being able to afford an excellent disabled therapist, and I would recommend, if you can, finding a disabled therapist, because then you don't have to do all the explaining. I would say it's about finding the right supports and community. I have a WhatsApp group of other disabled women, and honestly, we just have a little rant about it now and then, because that is an understanding and welcoming space where we're not going to get the 'Oh, they were just trying to be nice' responses. I think also it's about kindness, and this is something I've had to learn, is to be kinder to myself and to give myself those days where I go, ‘You know what, that was horrible and it impacted me and I need to look after my mental health, and I need to use the supports that I've developed, and actually, it's not a failure if I don't go out today because that impacted me’. So it's about finding the ways that you can be kind to yourself as well. And I'm – you know, I'm always happy to have a bit of a rant about it, so if I have the free time, you can always send me a message.

Catherine Walter:

Thank you. Okay, we have a couple of questions along these lines, and I'm – I was uncertain as to which one to pick, but I'm going to choose this one.

> ‘Hello, Dr Kavanagh, thank you so much for this excellent keynote. I am really enjoying it. I recently trained as an intervenor for people with multi-sensory impairment, deafblindness, and one of my activities – sorry, one of the activities was me in blindfolds and ear defenders being the deafblind child whilst my partner was the teacher...’

(I should say this without emotion…)

> ‘... who had to find a way of conveying a message to me about a new activity we were going to do. My partner chose going for a walk as the activity and chose to give me the message by making me wear a coat that belonged to a third person in the training. She just brought the coat and put it on me. I found this so uncomfortable and intrusive that to this day I still cringe when I think about it. My question is: What do you think is the best way forward or practice when working with children and young people for whom touch and physical proximity is crucial for learning and development?’

That's a very – you might want to unpack that, but that's the question. Thank you in advance.

Amy Kavanagh:

So my first response, and you probably heard the groan, was: I find simulation of disability in training repellent. I've actually had the experience of having to go through a training where other people were simulating blindness, and I was sat in the room as a blind person while other people simulated blindness with these spectacles and blindfolds and things that they have. And I had to listen to everyone in the room saying how terrible it was and how awful it was and how grateful they could take the spectacles off, and it was – it still makes me really upset to this day thinking about it. And I wish I had the references to hand, but there have been multiple comprehensive academic studies to show that simulating disability in any training environment does not impart proper learning. What it does routinely is it furthers misunderstanding of disability and it creates fear. Like, the biggest response people come away with is fear of disablement.

So that's my thought on that. And I think the example given demonstrates exactly why it's not a productive experience. There are amazing multi-sensory practitioners. I've had the privilege of working with some multi-sensory practitioners, and I personally in those experiences have favoured what is called a total communication approach, and that is where you continue to offer every type of communication to somebody to receive information and to respond to information. The big problem with those simulated exercises: it continues to assume that deafblind children are totally deaf and totally blind, which is quite unusual. Lots of deafblind children will have residual vision and/or hearing; and touch, when it is the only experience for sensory inputs, although like I say it's rare that it is the sole sensory input, it is even more important that that touch is consensual.

And from my experience, best practice is about gradually building up connections between the sensory stimuli and the activity. And using an object of reference, which is what the coat exercise was supposed to be, you do not – because it is meaningless. Just shoving a coat on someone is meaningless. And I knew an example where a young person kept being given their shoes. They were given their shoes to say 'We're going outside', but there was no connection ever made between the shoe and the outsideness. And so someone was just having an object shoved at them with no journey towards that meaning, and that's what's really important.

But yeah, I'll have a think. I know that in the UK, Deafblind UK has some really good resources. I know that there's quite a few conferences on multi-sensory impairment interventions, and of course the best solution is often: Talk to a deafblind adult. Learn from a deafblind adult. Have a deafblind adult lead the training, who can say 'As a child people repeatedly shoved a shoe in my face and I had no understanding of why'.

So yeah, that would be my top tip, go and speak to some excellent deafblind adult advocates who can inform and educate.

Catherine Walter:

Okay, thank you very much. I'm afraid I've – there's one more question and I'm making an arbitrary choice – well, not entirely arbitrary.

Amy Kavanagh:

That's your power, Catherine.

Catherine Walter:

I've tried to give you a flavour of the different sorts of questions, and there are questions we won't be able to answer, and you can decide what to do about that. But here's one that I think has a theme that has come up more than once.

> ‘I'm wondering if Amy can talk a bit more about how she sees the intersections between disabled activism and other activisms, such as black and feminist activism. How can those of us in different marginalised groups be useful allies to disabled people?’

Amy Kavanagh:

First of all, I would say that my introduction to disability activism was through black disabled activists because black disabled activists, especially in the US, are doing incredible work and hugely important work. Disability activism is too white. White middle class people like myself are grossly overrepresented in – you know, when that inclusion is there, which it rarely is, it tends to be white middle class disabled people, and I think it is really important that as an activist I am committed to an intersectional approach. I am a big champion of trans rights, and I am a huge supporter of Black Lives Matter movement.

And wherever I possibly can, I believe in passing the mic because, actually, there are experiences that I cannot speak to and I don't pretend to. And I would say I have learnt huge amounts, especially from – and a lot of disability studies theory and theory of kind of the body and consent comes a lot from feminism, and that idea of the public body and access to the public body has a lot of academic grounding in feminist studies, in feminist literature, which, like, I have drawn on somewhat. I would say Rosemary Garland Thompson is excellent reading on those intersections between feminism and disability studies, around the body and access to the body. To be a good ally, I think we just need to just keep talking and be in the same room because you know what, black disabled people exist, disabled women exist. Trans disabled people exist. You know, there are so many intersections and overlaps and marginalised communities that should and can uplift and support each other.

Now the one thing that really pisses me off, and I will swear because it's appropriate, and everyone needs to stop doing it, is something I see so often in the disability community is, for example, when there's a guide dog refusal, because that's my lived experience. I experience a guide dog refusal, a business refuses to let me in and says 'Your guide dog can't come in here', and they break the law. And so often other disabled people will respond in comments like 'If you were this marginalised group it wouldn't happen.' 'If you were black that wouldn't happen.' 'If you were Jewish that wouldn't happen.' 'If you were trans that wouldn't happen.'. And it is a lie. And it is offensive and it needs to stop, because we are not going to play the oppression Olympics. We are going to recognise that marginalised people experience intersections of different oppressions that are systematic and individual, and it is not an appropriate comparison, and I'm sick of it, and it needs to stop. Because black people get turned away from businesses all the sodding time. Trans people get turned away from businesses constantly. People face multiple marginalisations and discriminations, and acting like disability is this sole and somewhat pedestal-worthy discriminatory experience is bullshit, and we need to stop doing it.

Catherine Walter:

Thank you very much, and now I'd like to pass the microphone over to Caroline Kennedy for the Vote of Thanks. Caroline is the administrator of the Harassment Advisory Programme at the University of Oxford. Caroline?

Vote of Thanks

Caroline Kennedy:

Yes, I was honoured to be asked to be giving this evening's Vote of Thanks on behalf of the Disability Advisory Group and the Equality and Diversity Unit, which I work within. Amy touched on so many themes that I hear in my work running the Harassment Advisory Service and in my role as an Advisor in the Sexual Violence Support Service: consent, disempowerment, control, inconvenient truth, and the cost of speaking up and expressing your boundaries. Firstly I just want to say thank you to Catherine Walter and Sarah Stephenson-Hunter for making this event happen. They worked so hard to bring this to its conclusion, so thank you to them both. Thank you to the VC, who did try to open the event and to join us, but Zoom had other plans.

But finally, I'd like to thank you, Amy. Your talk was personal, powerful, challenging. I don't think there's enough words to describe how wonderful it was, but I think also you empowered us as bystanders. You gave us the tools and the tips and tricks on how we can be better to lessen that emotional labour. And I think you've created lots of champions tonight, so I want to thank you so much for giving up your time to talk to us and for sharing your experience, but also how we can be better bystanders. So thank you, Amy.

Amy Kavanagh:

Thank you so much. It's been an absolute privilege, and I'm always online to carry on these conversations, and if you want to send me a summary of those questions, I'll answer those that I can.

Catherine Walter:

That's wonderful. Thank you very much, Amy, and that's extremely generous of you to offer to answer the questions. I will send you a summary, and it just remains for all of us to be immensely grateful that we have a sibling like you to help show us the way. Many, many thanks, and to all of you, a good evening.

---- End of transcript ---

Amy Kavanagh’s details

Follow Amy on Twitter/Instagram: @BlondeHistorian

Work with Amy: www.amykavanagh.co.uk

Check out Guide Dog Ava on Twitter/Instagram/TikTok: @GuideDogAva

Resources

- Deafblind UK offers resources to support people with sight and hearing loss: https://deafblind.org.uk
- Glitch offers information on being an active bystander in cases of online abuse: https://glitchcharity.co.uk/resources
- Mermaids provides support for transgender young people and has a live chat or phoneline: https://mermaidsuk.org.uk/young-people/
- The Mix offers free counselling sessions to anyone under 25: www.themix.org.uk/get-support/speak-to-our-team/the-mix-counselling-service
- Rape Crisis has a phoneline: https://rapecrisis.org.uk/get-help/want-to-talk/
- Safeline offers online counselling and support to anyone over 18 who has experienced childhood abuse: https://safeline.org.uk/services/counselling-therapy/
- The Survivors Trust has a live chat and freephone line: www.thesurvivorstrust.org/live-chat-service
- Survivors UK for men has a live chat and SMS line: www.survivorsuk.org/survivors-uk-hub/#section-1

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