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#399: How attitudes disable: Rethinking our assumptions about people with impairments

VOICEOVER

This is Up Close, the research talk show from the University of Melbourne, Australia.

LYNNE HAULTAIN

Hi, I'm Lynne Haultain and welcome to Up Close. The way we understand disability has changed dramatically in recent decades, but according to our guest Eric Emerson, there are still some serious assumptions to be broken. The relationships between poor health, disability, and poverty are being revealed in data in many parts of the world. And with that, comes some challenges to government policy and more than that, to common perceptions about what disability is.

The way we understand disability means we are making all sorts of assumptions about health, well-being, and capacity which effectively marginalise people and perpetuate the problems. There's evidence to show that not only disability can result in poverty, but that poverty increases your chance of disability. What can be done to break that nexus?

Professor Eric Emerson is a pre-eminent researcher in disability health, emeritus professor at Lancaster University in the UK and working mainly now in Australia at the University of Sydney. He's in Melbourne for the launch of the Centre of Research Excellence in Disability and Health at the University of Melbourne, and we're delighted to have him join us for Up Close.

ERIC EMERSON

Thank you.

LYNNE HAULTAIN

Let's talk about what disability is and what it isn't, Eric.

ERIC EMERSON

I guess there are really two components to being disabled or having a disability. The first is that you have to have a significant health condition or impairment.

LYNNE HAULTAIN

That's physical, intellectual.

ERIC EMERSON

Physical, mental. Of course, many of us have long term physical or mental health conditions or impairments. I have - you can't see on the radio but if you were here you'd see that half my face is paralysed, and that's a long-term impairment, but I'm not disabled.

The second component - and that's what really, disability is about, is that you also need to face restrictions on your abilities to participate in society in some kind of important and meaningful sphere, whether it's civic participation, economic participation, which is related to your health condition or impairment.

The health condition or impairment is something which is personal, something that is part of you. The disability arises from the interaction between that health condition and impairment and the society in which you live.

LYNNE HAULTAIN

It's not who you are; it's what happens to you?

ERIC EMERSON

Absolutely. I'm not disabled because having a face in which only half works isn't a problem in the society in which I live; it's never been a problem for me. Imagine if I was living in a society in which people felt that - had a cultural belief that those people whose faces didn't work well was a sign of evil, then I would be disabled in that society. Or, if I was living in a society in which facial expressions were really, really important in communication. They are important in communication, but if that was a main mode of communication, then I'd be struggling.

It would be the kind of cultural beliefs or expectations etcetera need to be specific and interact with the health condition or impairment that the person has, that creates this problem of living in that society. It means people get excluded - socially excluded because of their health condition, not because the health condition does it but because the cultural expectations, the way society works, means that they are being excluded.

LYNNE HAULTAIN

We do it to them?

ERIC EMERSON

Absolutely.

LYNNE HAULTAIN

Society creates the construct in which this is declared disability, and that's not.

ERIC EMERSON

Absolutely, and there's a very interesting debate within disability internationally in terms of whether you talk about people with disabilities, or whether you talk about disabled people. In the UK, disability activists will talk about disabled people; people who have been made disabled by society and think that talking about people with disabilities suggests that the disability is inherent within the person. I know in Australia people like to talk about people with disabilities.

There's an interesting difference in the way we talk about these things which gives slightly different messages.

LYNNE HAULTAIN

And goes to, I suppose, the challenge to this understanding of disability which has ramped up over the last 30-odd years with disability activists as you describe.

ERIC EMERSON

Absolutely.

LYNNE HAULTAIN

What kind of in-roads have they made in the understanding of the way in which we comprehend disability? Do you think that's much clearer now?

ERIC EMERSON

I think it is for many people; I think it is for many important institutions like governments, it is on an international scale in relation to the UN Convention on the Rights of Persons with Disabilities which clarifies what disability is and what it isn't. I really don't think that understanding that disabled is done to people by society, has got through to kind of lay understandings of disability. I think many people - many professions still seem to see disability as just ill health, certainly, in the area in which I'm working - public health, that's the primary way that people think about disability; it's ill health, isn't it? These are just ill people.

LYNNE HAULTAIN

Let's talk about health because that's another dimension to this. You've got extensive research to demonstrate that there is poorer health in people with impairments and who are disabled to use the English terminology. It doesn't necessarily relate to their underlying condition?

ERIC EMERSON

No.

LYNNE HAULTAIN

You've got people who have mental health conditions or intellectual health conditions and disability, but who have high blood pressure or diabetes which doesn't necessarily connect in any way with their disability. What's going on there? We've got poorer health but not in the ways that necessarily connect with the impairment.

ERIC EMERSON

Sure, clearly there are some instances in which the poorer health of people with disabilities is connected to their impairment. For example, we know that children with Down Syndrome are at higher risk of congenital heart defects which is clearly life-threatening and detrimental to their health. All the evidence suggests that's about Down Syndrome, there's something about the chromosomal abnormality which creates Down Syndrome which also does this.

Sometimes the poorer health of people with disabilities is related to their impairments, but I guess the puzzling thing is that for a lot of people, the poorer health cuts across so many different aspects of their lives that it's difficult to understand any biological mechanisms or processes which link the impairment to poor health. Why should people who have difficulty understanding and communicating of it have such higher rates of mortality, of poorer mental health etcetera?

That's been one of the puzzles, why do people who have difficulty with relation to mobility have poorer mental health? It doesn't seem to be related in a physical way to their impairments. That's one of the kind of things that we've been looking at for a decade or more now, and I guess we've come to the position of thinking that the primary factor which is driving the poor health of many people with disabilities, is nothing to do with their impairment at all. It's about the disadvantage they face in the world into which they are born, grow up, work, live etcetera.

It's the disadvantage faced by people with disabilities which really generates and creates their poorer health. It's not about impairment; it's about being disabled. It's about being marginalised and disadvantaged in the society in which you live. We see poorer health amongst other marginalised and vulnerable groups, amongst economic migrants, amongst Aboriginal/Torres Strait Islander people. This is about the effects that society have on marginalising people and damaging their health.

LYNNE HAULTAIN

Would you equate disability with disadvantage?

ERIC EMERSON

Absolutely. Impairment, that's one thing, but the disability that people face is about disadvantage. It is about social exclusion, then it's about marginalisation, and we know that socially excluded and disadvantaged and marginalised groups around the world have poorer health. People with disabilities are one of those at-risk groups. We need to understand and accept that in terms of formulating health policy and practice.

LYNNE HAULTAIN

Let's have a look a bit more closely at what happens with people with disability. Lower incomes, lower family incomes, greater financial insecurity, possibly lower education attainment; is that the sort of picture that we're creating?

ERIC EMERSON

Yeah, absolutely. In a sense, it starts from birth; it starts before birth because people

born into more disadvantaged circumstances are more likely to acquire impairments that are associated with disability in the society in which they're living.

LYNNE HAULTAIN

That flips it the other way; that's saying that poverty creates disability?

ERIC EMERSON

No, that's saying that poverty creates impairments, which is separate - it's a separate issue but for many of the impairments that are associated with disability in certainly an Australian society or British society or virtually any other society, most of those impairments which are associated with disability, tend to be more common amongst people living in poorer circumstances, and particularly amongst children growing up in poorer circumstances.

LYNNE HAULTAIN

Like?

ERIC EMERSON

Developmental delay, intellectual disability, child mental health. There are very strong relationships between exposure to adversity in childhood prenatally, and the risk of acquiring a developmental delay.

LYNNE HAULTAIN

Deafness for example?

ERIC EMERSON

Deafness, absolutely. Some of the areas in which you see really strong relationships are deafness and all the intellectual and cognitive problems that children may acquire. Dyslexia is a very strong relationship between exposure to adversity in childhood and the probability of acquiring dyslexia.

It doesn't mean that everybody who has dyslexia has an adverse childhood at all, but it just increases the risk.

LYNNE HAULTAIN

Eric Emerson is Professor of Disability Population Health at the University of Sydney, and today on Up Close we're exploring the way we understand disability and the links with poor health. I'm Lynne Haultain.

Eric, we have people with impairments who will feel marginalised and become disabled?

ERIC EMERSON

Yep.

LYNNE HAULTAIN

We have people who are growing up in socially disadvantaged environments and are

more likely to become impaired and disabled. How do you break that down, what needs to happen?

ERIC EMERSON

I guess you really need to look at the different pathways that lead from impairments through disadvantage through to disability which requires [unclear] disadvantage. For example, we know that growing up in adverse circumstances increases the risk of cognitive delay, developmental delay. We know that if you go to school with a developmental delay and not as good at language as other kids and not as good ability to concentrate as other kids; you're not going to get the best out of the educational system. We know that if you leave school with poorer qualifications you're not going to do well in the labour market, you're more likely to be unemployed etcetera.

It's identifying those pathways which kind of run through life and thinking, well what can we do at different stages to intervene effectively, and especially to target those children, those families, those individuals who are at most risk.

LYNNE HAULTAIN

If we're talking about the disadvantages of housing, nutrition, income, family security, that kind of stuff; why is it we don't see higher levels of disability and that kind of marginalisation in poorer socio-economic countries?

ERIC EMERSON

We do. There's been a huge amount of work over the last decade or so, primarily led by the World Health Organisation to try and understand why we see such huge differences in life expectancy for example from childhood, childhood life expectancy, childhood under five survival rates, child development, why we see such huge variation between countries around the world and within countries around the world.

We do see staggeringly large differences in, for example, the chances of child surviving to age five around the world. The poorer the country, the higher the risk. In rich countries, it's slightly different, but there's a very, very strong relationship. The same appears to be the case for disability as well. Disability is one of those things that health researchers have largely ignored, so I guess the quality of the information isn't as good as we'd hope.

For example, we're currently working with data provided by UNICEF looking at the extent to which children under five have significant levels of developmental delay. The rates that we're seeing in the world's poorest countries are far, far higher than the rates we see in the world's richer countries; staggeringly high, 30 to 40 percent of children using the same measure appear to have significant developmental delay in the world's low-income countries, compared with 0.1 or 0.2 per cent.

LYNNE HAULTAIN

That's extraordinary.

ERIC EMERSON

Yes, and there's been some really good work done trying to estimate how many million children under five fail to realise their developmental potential. The numbers are always a bit flexible, but we're talking 250-500 million children a year, and they are nearly living in the world's poorest countries.

LYNNE HAULTAIN

Now, Eric, I'd really like to spend a bit of time talking about discrimination because it seems to me that that's part of this picture that we're painting around marginalisation and what creates disability in itself. If disability can make people poorer, and poverty can increase your chance of being disabled, it's pretty clear that what we've done is structure a society in a way that is having a very profound impact and we are feeding that with this discriminatory response, and the creation of the thing which is called disability, because it's in our minds rather than in anybody's body.

How does that work? How does disableism as it's called in some parts of the world, feed into this spiral?

ERIC EMERSON

I guess there's probably two broad components to it. The first is the extent of which we structure our society and access to the institutions within our society which may disadvantage people with particular types of impairments or health conditions, to the extent that we create buildings in which the only way you can get up to them in steps, then we are disadvantaging and creating difficulty of access for people who have difficulty walking or use wheelchairs. The extent to which we structure health services, so that you need to be able to be a very good communicator and very articulate, and really good at problem-solving even to figure out how to access those health services, is discriminating against and disadvantaging people with cognitive impairments or intellectual difficulties.

LYNNE HAULTAIN

There's structural and sort of institutional...

ERIC EMERSON

Absolutely, and nobody's planning services or designing buildings to exclude disabled people. It's a problem of omission of not thinking about how we develop our cities or how we build buildings or how we create services which are more inclusive.

LYNNE HAULTAIN

I would have thought that has improved significantly?

ERIC EMERSON

Absolutely, yes.

LYNNE HAULTAIN

Transport, access.

ERIC EMERSON

It is improved significantly for some groups of people with disabilities. It is improved significantly, for example, if you have mobility difficulties; we have ramps in most buildings, not everywhere, not even at the University of Melbourne. Generally, it's easier to get around in a wheelchair than it was say 20-30 years ago. Of course, that's not the case in many other countries in the world.

For people say with significant intellectual or cognitive impairments, well, it hasn't got that much easier. In fact, to an extent, you can think it's actually getting more difficult the more we are dependent upon more complex technologies, the more difficult it is to negotiate your way through our institutions. I'm sure we've all had those really irritating attempts to try and book an appointment with our doctor when they get through to some automated telephone answering system, if you want dah-dah, press one, if you want dah-dah-dah press two. Some days I struggle with those, and I think to myself, what was number one. If you have an intellectual disability, how on earth do you even book an appointment with your family doctor?

I guess, the advantages we've seen tend to be specific and they tend to have gone to those groups of people with disabilities who have the most effective lobbying and advocacy behind them. Other groups of people with disabilities with different impairments have really not benefited. I don't think people with mental health problems who have disabilities have particularly benefited and much better off than they were 10-15 years ago in Australian or British society. In a sense, we picture disability as something visible; the disability symbol is a wheelchair or a white cane. That's got through to an extent to people, but most disability is not visible. People may look completely normal or whatever, but that doesn't mean they don't have a disability, and that group of people are particularly disadvantaged.

LYNNE HAULTAIN

There's that sort of structural discrimination, but there's also some just plain mean, nasty treatment that people experience.

ERIC EMERSON

Yeah, absolutely. There's also the - I guess the more aggressive, more interpersonal discrimination in which people are just preventing people because they don't want that kind of person around.

LYNNE HAULTAIN

How common is that in experience?

ERIC EMERSON

I think it is relatively common. Some of it is just unthinking, and again, it kind of relates to a disability not always being obvious. We're doing some work at Sydney looking at how young Australians with disability experience discrimination in public places, discrimination on say things like public transport is quite common, but a lot of it is unthinking, it's, well that person looks perfectly normal but they're sitting in a disabled seat, so you get glances, you get comments. That person could well have a

disability. People don't think because we have this image in our head that disability is about wheelchairs and that's it and if you look kind of young and healthy then, well, you shouldn't be doing that.

I guess at the other extreme there some horrendous examples of crimes being perpetrated against people with disability either because they're easy targets or because people are scared of them or don't like them or whatever, and that's particularly a problem for people with mental health problems.

LYNNE HAULTAIN

That feeds this marginalisation, because if you are the recipient of that kind of fear or treatment, aggression whether it's institutional or interpersonal, your confidence takes a hit.

ERIC EMERSON

Yeah, and there's very good evidence, not so much from the world of disability but from studies that have looked at racial or ethnic variations in health, the day-to-day interpersonal discrimination that people experience has a significant impact on their health, particularly their mental health.

LYNNE HAULTAIN

What you've referred to as the corrosive effects on well-being?

ERIC EMERSON

Yes.

LYNNE HAULTAIN

Which seems to me to have a couple of effects. One, it goes to your capacity to hold down a job or maintain an educational pathway, all the sorts of challenges that it presents there, but in itself it also becomes part of the disability?

ERIC EMERSON

Absolutely.

LYNNE HAULTAIN

It creates a kind double whammy effect, I think, on breaking out of this mindset.

I'm Lynne Haultain and today's Up Close we're talking to Professor Eric Emerson about disability and the relationship between poverty and disability.

LYNNE HAULTAIN

What can we do to return to that question around the changes that need to take place in order to address this? I know that you've set out a very interesting response to this which starts with social stratification, it addresses that big notion of, we have created as a society this concept of disability. How do we then undo that and open things up with access to education, to work, to housing, to all the things that we would, as a general community, take for granted? It really is about evening the

playing field.

ERIC EMERSON

Yeah, absolutely. For those countries in the world that's ratified the UN Convention on the Rights of Persons with Disability, that's what they've signed up to do, to progressively realise the rights of people with disabilities to participate in all aspects of society, to have good health, to have a good well-paid respectful job, to have a family. That is something that we need to do, and clearly many countries are attempting to do that.

There's good examples of legislation etcetera of initiatives to try and break down the barriers that people with disabilities face in participating in society, particularly in areas of architecture and design of buildings and design of cities which are significantly more disability friendly for people who have motor impairments than they were before. I think also for people with some types of impairments, access to employment; it's not as good as it should be, but there are areas in which we can see some significant progress. I think if you look at education systems, there has been progress in identification of children with disability and providing support that children with disability might need.

Clearly, things have improved, the barriers have been broken down to enable people with impairments of particular types to not be disabled by those societies, but we've still got such a long way to go.

LYNNE HAULTAIN

There's the broad governmental, institutional response, but there is also a communications piece to be undertaken, isn't there?

ERIC EMERSON

Absolutely. We have to change minds and hearts as well as buildings, and I think that's proving more difficult. Again, it is one of the specific obligations that countries have signed up to when ratifying the UN Convention, to address the public stereotypes about disability. Buildings is one thing, but we're not probably seeing the rate of progress or in some instances any progress in changing public attitudes about disability that we really hope to see and we really need to do.

LYNNE HAULTAIN

You know that that's not shifting because we're still seeing episodes of discrimination, or is that evident?

ERIC EMERSON

It's difficult to get hard evidence on these things but yes, I mean we're certainly still seeing higher rates of exposure of people with disabilities to crime. We're just doing something and looking at exposure to crime among people with disabilities in New South Wales and the gap between people with disabilities and people without disabilities is just growing year-on-year. It's not there's more, but the reduction in exposure to crime and violent crime amongst people within New South Wales is

going down, but it's going down faster for people without disabilities than it is for people with disabilities. The relative disadvantage they're facing is growing, and that's common in many areas of life. You look at employment, things are getting better for people with disabilities, but they're getting there faster for people without disabilities.

While things are improving, they're getting worse at the same time, if you're interested in the relative disadvantage that people face. It's that relative position that you hold in society which is important, and that's what poverty's about; poverty is about your position relative to other people in society, it's about what that says about you in the society in which you're living.

LYNNE HAULTAIN

Eric, what about people with impairments who are disabled and their sense of their own capacity in all of this? You talk about that in terms of supporting the development of resilience for disabled people. How is that growing?

ERIC EMERSON

One of the issues is that we know in all aspects of health that, I guess exposure to adverse conditions or exposure to a virus, some people catch the cold, some people don't. There's an important question that we need to ask about why are some people more vulnerable or resilient in similar circumstances. What we've learned is that while there are some aspects of the individual, in the sense of personal characteristics which make you more resilient, for example, if you're good at communicating, and you're good at problem-solving, you're generally more resilient than people who aren't good at communicating and aren't good at problem-solving. These are personal things, and some of those are easy to change, and some of these are not easy to change.

In terms of, more importantly, resilience is about - again, it's about the society in which you live, it's about the society in which you personally live rather than the broad society. What resources do you have, how many friends do you have, who can you call on, is there a shoulder you can cry on? Things happen to all of us and what we do within the face of adversity is we usually turn to our nearest and dearest or spend lots of money and go off and climb a mountain or whatever it is. The issue for many people with disabilities is the disadvantage not only in relation to they're more likely to face adversities in their life, they're also disadvantaged in that they have less access to the kinds of resources that everybody else uses when faced with adversity. Because of their social isolation, they have fewer friends, they have smaller social networks, they are less connected with the community around them because of stereotypical attitudes and the way people are socially excluded, they have less access to money, they have less access to wealth and less access to power, which puts them at a disadvantage.

On the one hand, they're more likely to be exposed to adversity, and on the other hand, as a group generally, they're more likely to be vulnerable to the effects of that exposure. Of course, there are some examples for the exact opposite and some

remarkably resilient people with disabilities as there are for people without disabilities. Taking the broad picture across the group of people with disabilities, there is an issue there. We need to be working on both sides of this; we need to be creating societies in which people with disabilities are no more likely to be exposed to the common adversities of life than you or I. That's not happening at the moment, we need to make much more progress there. We do want a level playing field; we want an equal society.

We don't have a magic wand, we can't, tomorrow, create an equal society so what else can we be doing at the same time? It's not an alternative; it's not one or the other; what else can we be doing at the same time to help people with disabilities become more resilient, to have more friends, to have something in their life they can feel really proud about? That's something which makes us resilient. I don't mind about that because I know I'm really good at this, and I think there's a lot more that we can be doing in that area to create a society in which people can have more friends, more support and can achieve things that help them at times of adversity, and have more money etcetera.

All these things are important, and all these things will help people with disabilities as they do, you or I, become healthier.

LYNNE HAULTAIN

You've painted an extremely powerful picture, Eric, of the challenge before us but I think, as we said at the outset, the understanding of what disability is and what it is not, is something that we all need to grapple with at every level. Thanks again for your time.

ERIC EMERSON

Thank you very much.

LYNNE HAULTAIN

Today I've been speaking with social epidemiologist Eric Emerson, Professor of Disability Population Health at the Centre for Disability Research and Policy at the University of Sydney. You'll find details of some of his publications on the Up Close website together with a full transcript of this and all our other programs.

If you like Up Close you may want to check out another of our podcasts, Eavesdrop on Experts which features stories of inspiration and insight in conversation with researchers.

Up Close is a production of the University of Melbourne, Australia. This episode was recorded on the 28th June 2017; it was produced by Eric van Bommel, with audio engineering by Gavin Nebauer.

I'm Lynne Haultain, thanks for listening, and I hope you can join us again soon.

VOICEOVER

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