



Ear to Asia podcast

Title: Living with disability in Asian societies

Description: In the Asia-Pacific region, it's estimated that one in every six people is living with a debilitating physical or cognitive impairment, and that figure is set to grow. So what is the lived experience of people with disabilities and the people who support them in these challenging environments? Population health researchers Dr. Cathy Vaughn and Alex Devine, and social entrepreneur and polio survivor Huy Nguyen, discuss the plight of people with disabilities in Asia. Presented by Ali Moore. An Asia Institute podcast. Produced by profactual.com. Music by audionautix.com.

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Ali Moore: Hello. I'm Ali Moore. This is Ear To Asia.

Cathy Vaughn: Where you've got a more robust economy, there is greater investment in infrastructure, generally. So there are many parts of Asia where physical accessibility, for example, is very good whether that's in Japan or Korea. But I would say there's quite a bit of inequality or inequity in many countries in the region.

Alex Devine: If a family has a child with a disability, and the social support and the social security is not there, then that family may find it very difficult to continue working at the same level, and therefore, their income starts to drop. But also therefore their capacity to care for their child with a disability starts to drop.

Huy Nguyen: I had opportunities to hear a lot of stories in various different countries from Timor to the pacific islands, and of course, in Asia as well - Cambodia, and recently, Vietnam. What's been really amazing is to see and to reflect on myself, as an individual, on how to view disability in those different lenses.

Ali Moore: In this episode, living with disability in Asian societies.

Ear To Asia is the podcast from Asia Institute, the Asia research specialist at the University of Melbourne.

Life can be challenging enough for people with disabilities in wealthy



western countries, but what about for those in developing nations where quality of life and meaningful economic participation are a far tougher ask?

In the Asia Pacific region, it's estimated that one in every six people is living with a debilitating physical or cognitive impairment. They often have fewer rights and protections than their counterparts in the rich world. In the face of greater discrimination and exposure to violence. So what is the lived experience of people with disabilities and the people who support them in the Asia Pacific?

How do cultural attitudes towards disability colour that experience and how are people with disabilities recognised and assisted by their governments and other institutions? Joining me to discuss these questions are three people who research or work in the disability sector across a number of countries in Southeast Asia.

Ali Moore: Dr. Cathy Vaughn of the Centre for Health Equity and the Melbourne School of Population and Global Health. Alex Devine, a senior research officer at the Nossal Institute for Global Health as well as a doctoral student and engineer and social entrepreneur Huy Nguyen, founder of Enabler Interactive which develops training technologies for use in disability and aged care. To all three of you, welcome to Ear To Asia.

Cathy Vaughn: Thank you Ali.

Huy Nguyen: Thank you.

Ali Moore: Cathy, let's start by drawing a picture if you like of people living with disabilities in Asia. The UN estimates that the number is 690 million. Do you think that's accurate?

Cathy Vaughn: I think it probably is. The work that's been done into modelling the proportion of people in a population that have disability has been going on for a long time. There's a lot of people who have put a lot of effort into getting an accurate idea of the proportion of a population who have some kind of impairment, and yes, I think that is an accurate representation.

Ali Moore: You say some kind of impairment. Alex, do the numbers encompass all disabilities whether they're physical, whether they're intellectual?

Alex Devine: Yeah, absolutely. I think the modelling that has been done by agencies such as the WHO and the UN World Bank definitely do encompass all types of disabilities so whether that be a psychosocial disability associated with someone's mental illness, whether it's a cognitive disability or a physical or intellectual disability. I think sometimes what we don't have though is an accurate picture at each country level. We have fantastic modelling based



off and on western country data collection, but across the region, we have still very different ways of collecting data on disability both within countries and then across countries as well.

Ali Moore: It's interesting that you make that point because while the UN estimates the 690 million, it also talks about a larger underestimation if you like of the number of people with disabilities and in fact so large they put that at some 450 million. Huy, why do you think that there is such an under reporting.

Huy Nguyen: Yeah, I think it's all to do with how it gets translated, the terminology, especially when we get to the space of non physical disabilities and non physical impairments and how the locals sort of understands that. It translates to how we ask the questions on the ground to get accurate data and I think that's quite missing. The nuances behind that and the sense locally, there's a whole range of challenges with that, but I think it's how it gets translated from what we understand is a disability or different impairments, cognitive et cetera, how that gets translated and asked questions locally.

Ali Moore: Is it also though about how people are prepared to answer those questions?

Huy Nguyen: Yes. From that perspective, are they comfortable to answer that because in some of the spaces I've seen, it's generally quite taboo to speak or a little bit of stigma in terms of speaking out about your family members who have a disability because you're disclosing who your family member and what sort of impairments or disadvantage they may have and how others and neighbours can get to know about that so there's absolutely those barriers.

Ali Moore: Cathy, would you agree that there are sort of two sides to this discussion? There's the cultural overlay, the social context if you like which can take into account personal prejudices and then on the other hand you've got the economic or the infrastructure, the physical built environment that the government funding side. There's sort of two quite distinct elements to this conversation.

Cathy Vaughn: Yes, I do agree that there are two quite distinct issues that need to be addressed through policy and programmes and interventions, but I also think they're quite linked because if you have a community where there are high levels of prejudice around disability and discrimination against people with disability because of personal attitudes. People seeing a person with a disability as somehow lesser, than there won't be the investment in addressing the barriers to economic participation, the physical infrastructure, the communication technology that might be



needed to support peoples full and equal participation in communities. There are two separate sides, but I think they're sides of the same coin, that they're quite linked.

Ali Moore: Alex, they have to be addressed at the same. You can't do one without the other.

Alex Devine: Yes, absolutely. Sometimes it's very much a staged approach and I do think it's also very much about how an individual is placed in their social and cultural context as well. You can have someone living in a very well infrastructure and setting, but still have a high amount of stigma. You do have to be able to address all the various barriers in a comprehensive way.

Ali Moore: Huy, tell us a little bit about your story, how you came to use a wheelchair and what you see as the over riding issues facing people with a disability in the region?

Huy Nguyen: The short version of my story is I contracted polio when I was 18 months in Vietnam, quite a poor community. At the age of six, I moved to Australia, grew up in Canberra. I was a severe case of polio where I used a wheelchair full-time and in a way I was privileged to grow up and to learn in a mainstream school, an environment where you're more or less forced into that environment and to gain those social skills. Later in life after a few various challenges and questioning myself, my own identity, not just my own disability with cultural and all that stuff as well. I went to dig deep into this to research about disability and learn about more about myself along the way. To rephrase, I gained a disability because of terminology that came. Before that, I was just different. I knew I was different. The other kids still hanged out with me. We still got up to mischief.

Huy Nguyen: But to really get into it intellectually, academically sort of gained at that point, I gained a disability, both that I had significant opportunities to hear a lot of stories in various different countries, particularly more challenging countries from Timor to the Pacific Islands and of course in Asia as well so Cambodia and recently Vietnam. What's been really amazing is to see and to reflect on myself as an individual and just take that perspective, as well, on I guess – how to view a disability in those different lenses.

Ali Moore: How different would your life be in you'd stayed in Vietnam?

Huy Nguyen: It would be significantly different. I can't say if it's worse or better because there's a very different way each community approaches disability. One wonderful thing about, in the general kind of way, about Asian societies is very family oriented so you get support very much from your family. That still gets carried across here in Australia because I grew up with an Asian family. That's been amazing to be able to have that support, have that safe



environment, but at the same time, I've always fought to do things myself to be independent to mix with Australian culture or a more western culture to be more independently so having a blend of both and being able to have both of those has kind of contributed to my success. I think it would have been significantly different, probably a lot more challenged actually in terms of actual access and physical barriers and educational barriers as well.

Ali Moore: We talked there about Vietnam, but we can't generalise across Asia. Alex, do you have any sense of the broad differences that we're likely to find in the lives of people with disabilities in Asia if we compare them to more developed, more wealthy countries?

Alex Devine: Yes. While the rights of persons with disabilities has been a universal declaration that has been signed by many countries as well as across the Asia and Pacific region, I still think some of the attitudes towards people with disabilities probably less progressed than they are in western settings. I think partly that's because of disability and some of the cultural beliefs that are associated with disability, but also because in a lot of other settings, this sense of individual rights is probably quite different in say Australia as it is to China. Therefore, using the convention of the rights or persons with disabilities had profound effects for many people. It still perhaps hasn't influenced all levels of society right from the legislations and the constitutions that countries have to the investment that they provide for different sectors of society that may benefit people with disabilities.

Ali Moore: Cathy, how different is that response depending on the level of development in a country, the wealth of a country? That sort of thing. I mean, if you look at the difference between Cambodia and Australia or even China and Cambodia, is it linked to the level of development?

Cathy Vaughn: In part, I think where you've got a more robust economy, there is greater investment in infrastructure generally so there are many parts of Asia where physical accessibility for example is very good, whether that's in Japan or Korea. Countries like Korea actually have very advanced rehabilitation services for people with physical disabilities, but I would say there's quite a bit of inequality or inequity in many countries in the region. I've actually said that applies in Australia as well. If you live in a rural or remote setting, your access to services is going to be a lot poorer than someone who lives in a capital city. In countries that I've worked in, in the region for example Manila in the Philippines, if you come from a family that lives in a wealthy part of town, you will have completely different access to services and opportunities and there may also be quite different attitudes in the community towards disability if you live in a poor fishing village on a remote island.



- Ali Moore: Which goes to education as well, doesn't it?
- Cathy Vaughn: It goes to education. It goes to exposure. It sometimes goes to advocacy. It's extraordinary what individual advocates can do in different communities to really change the way that people around them think. Sometimes large scale change can happen when there's an advocate in a very senior position of power so I'm thinking back to historically in Pakistan, they were one of the first countries to embrace community based rehabilitation and it's because the presidents' daughter had a disability. Sometimes it takes that personal connection for people to see the barriers that people have been long facing in their community around disability and to try and do something about it.
- Ali Moore: Huy, tell us a little bit about Cambodia. A country which has received a lot of development assistance especially aimed at people with a disability.
- Huy Nguyen: Yeah, my time there was quite eye opening. Besides the work trips I've done, I'll come up from I guess a personal perspective. I went there for holiday, travelling by myself just to push it out there and see what happens. It's actually quite a comfortable kind of country for a visitor who has disabilities to go to because people are really nice, really opening, really welcoming, don't always stare you down like what is this person doing here in a way. Of course, infrastructure is very challenged and what you've just talked about earlier around advocacy and seeing enough people around, you barely see anybody let alone people who kind of represent where you push forward in the community and you're quite right to have people who have significant disabilities or family members who have that to really influence at the senior levels. Whilst there's almost every NGO under the sun in Cambodia, there's a lot of I guess focus ongoing straight to the DPOs.
- Ali Moore: DPO?
- Huy Nguyen: Disabled Peoples Organisation, the peak body that represents people with disabilities in Cambodia. They get all sorts of resources, funding, et cetera, but I still don't really see how much advancement that has made and one of that's because it's getting so used to this model of externals coming in, providing resources, capacity building, training the trainer and what exactly it goes to, but I managed to actually get to visit some of their groups of people with disabilities who haven't received the same resources as the main peak bodies and for them, they're doing incredible things as well. They don't actually have been highlighted as much.
- Ali Moore: You said yourself, very, very warm people. Very welcoming people, but if we look at the cultural overlay, what is the attitude towards people with a disability within their own families for example?



- Huy Nguyen: Really still quite challenged and especially it goes to non visible disabilities, I think it's even more challenging because it goes to what was mentioned before about education or understanding and knowledge about what is the different types of disability, what are the causes of this because that's where a lot of my line of work is embedded into that. How can we break that down into something that people can understand, add a bit of science to it, what's behind the cause of someone's intellectual disabilities, et cetera. Of course, those things can be quite complex and difficult to understand for a family in a rural community. It's very challenging in those particular families.
- Ali Moore: Alex, Cambodia of course is a Buddhist country. Does that affect the way that people view disability?
- Alex Devine: Historically absolutely. I think as in many other Asia and Pacific countries, there has been a link between disability and say karma and that disability may be associated with sins of a past life. That I think we have seen really change over the last 10 to 20 years in Cambodia. I think when we've done our research there, people can remember being children and knowing other children that may have been taken away from the village because they had a disability. I think the peak bodies and also the DPOs at the local level have been really working hard to try and improve community understanding of both the causes of disability, but also the rights of persons with disability. I think the challenge still in Cambodia as opposed to China where they've got similar legislation say for example in terms of employment quotas whereas China has a lot more resources to implement and monitor those legislations and they also use that as a revenue to then reinvest in the area of disability.
- Alex Devine: Cambodia has similar legislation, but not the resources to monitor say employment of persons with disabilities whereas they're really relying on that function to then reinvest in local Disable Persons Organisations. I think some of the really good work that DPOs are doing in the country are working with religious leaders. Religious leaders still hold a lot of clout and quite a high platform and they're very connected to their communities so if you have your religious leader talking more positively around both the causes and the rights of people with disabilities, then that really does start to filter through into the community as well.
- Ali Moore: Cathy, that problem of having very good laws on paper, but then implementation and follow up and enforcement, that's not just a problem in Cambodia, is it?
- Cathy Vaughn: Absolutely not. For example in the Philippines, there's also a quite high level, very high level legislation around disability and the rights of people with disability to access services, opportunity, information on an equal

basis with others and yet the ability of the government to enforce that is very limited. It would be the same across many of the Pacific countries, I mean, many parts of the world. It's the monitoring and the enforcement of legislation and sometimes the structures around that so that you may have as Huy was saying, one peak body that is getting bombarded with requests and responsibility to monitor, to be the spokesperson for people with disability and they can't do it all. There's not perhaps the investment in decentralising that across the country to make sure that there's someone who can represent the perspective of people with disability from all kinds of parts of the country.

Ali Moore: In the Philippines, you've looked particularly at violence against people with a disability especially women. Can you tell us a bit about that research because the UN talks about "a pandemic" of violence against women and girls with disabilities. That's an extraordinary word to use, isn't it?

Cathy Vaughn: You could say that there's a pandemic of violence against women and girls full stop globally, but the situation is substantially worse for women and girls with disability. There's also high levels of violence against men with disabilities. Violence against people with disabilities is a really significant issue that's under recognised, that needs to have research done in a local context to understand the nuances of that because certainly from our work in the Philippines, not all women and girls with disability are at equal risk of experiencing violence. Women with intellectual disability, women with communication impairments. So, for example, if a woman is deaf and doesn't have sign language that can be understood by anyone outside the family, so has informal sign language rather than Filipino – the official sign language, then her ability to report sexual violence or violence perpetrated by someone within the household is almost non-existent because the only way she can communicate outside the family is through a family member. It makes it very difficult for women to access justice and perpetrators of violence are often quite opportunistic and will take advantage of women where they think they can get away with it.

Ali Moore: We've seen this in Australia and we're seeing this in the US. We're seeing this in some of the wealthiest countries in the world. Do you think it is a particular issue in the Philippines?

Cathy Vaughn: No, no. I think this is a global problem. I think that the access to justice is also a problem in Australia and there's a lot of-

Ali Moore: And reporting.

Cathy Vaughn: Absolutely. It's not just a problem in low income countries in the region. I think perhaps there are greater challenges in accessing services and supports in low income countries because they're so overwhelmed



anyway. Any woman experiencing violence will have difficulty accessing services and supports, but if you're a wheelchair user and the only counsellor who you can talk to about violence is on the third floor, you don't have a choice. There is not the services there and certainly the work we did in the Philippines, some of it was around very basic things like have a facility where there's ground floor access and make sure the doors are wide enough for people to get it. If you're going to train people, make sure that you have access to sign language interpreters and so on.

Ali Moore: Huy, access to services is one thing. You have to know they're there. I mean, is there a widespread knowledge of the rights and the availability of assistance for people with disabilities?

Huy Nguyen: The quick answer is no. But I'd just to make a couple of notes before. Even right now in Australia, we're just starting our Royal commission on the violence and abuse of people with disabilities. In Australia after many, many years of battles to get to this point, let alone thinking of other countries is you don't have the capacity or even have the resources to do that. The access for the actual people themselves to raise a voice, there's obviously multiple challenges, but there are probably potentially ways we can leapfrog a couple of processes, couple development steps in order to allow that. For me obviously coming from a technology background and working closely with people noting one colleague whose doing SMS chat bots to access information about domestic violence and how you can help that. Those kind of things can be introduced quite quickly.

Ali Moore: Using social media to tell people what they're, not just what they're rights are, but what services are available, how they can get help.

Huy Nguyen: Absolutely. Even easier now with SMS and we're not talking doing the internet. We can use that SMS to get access information on where I can go discreetly. That's my bit of my shout out to my good friend who's doing that and it's called Hello Cass. To be able to discreetly find that information that's very accessible because that's one of the biggest challenges I guess for us. People with disabilities in general is accessing or having information that's easy to access.

Ali Moore: Alex, what about how the rights exist on paper. Of course, on paper is one thing, implementation is another, but to what extent are the rights of people with disabilities actually legislated? For example in Australia, we have the Disability Discrimination Act. I know that there's a number of governments that have enacted anti-discrimination legislation, but to what extent is it I suppose first of all enshrined in legislation and secondly taken seriously?

Alex Devine: It is very mixed across Asia and the Pacific. There's still a number of



countries that don't have legislation that legislates against discrimination and sometimes that legislation doesn't cover all aspects of society so it might cover education or it might cover employment, but it still might not cover the right to vote or it might not cover the right to own land. I think the anti-discrimination acts are very different in a number of countries and again, I think it comes down to that capacity of countries and the willingness of countries to then monitor how they are implemented. Not many countries have a human rights commission such as Australia or a disability specific commissioner as well where people can report on violations of rights. Also, a number of people that we have worked with, their awareness of their rights is so low or their awareness that they're actually experiencing violence. Many women with disabilities might not recognise a form of violence that they're actually exposed to.

- Alex Devine: Not only is it difficult for them to report on it, but if they do manage to leave a relationship that is violent, the support networks or the social security network's not available. Women-
- Ali Moore: They're trapped effectively.
- Alex Devine: They're both trapped or if they do manage to leave, they find themselves in equally difficult circumstances.
- Ali Moore: When it comes to legislative rights and enforcement, what are the political obstacles to that?
- Alex Devine: Perhaps if we go back to the Philippines where they have fought for a long time to introduce rights to sexual and reproductive health for-
- Ali Moore: In a strongly Catholic society.
- Alex Devine: In a very strongly Catholic society. So their legislations that they have introduced are constantly under debate in the parliament. The other issue is that if for example you go to a hospital that the leader of the hospital is Catholic, they will perhaps create barriers to the procurement of both contraception, but also other medicines that all women may require to support their sexual and reproductive health. The other issue that we see is health nurses may be very happy to provide education to women with disabilities around sexual and reproductive health if they're married, but the assumption is that women with disabilities don't marry and they don't have children, therefore they don't need sexual and reproductive health. [crosstalk].
- Ali Moore: The flip side of that though that is in a country with a strong belief in a right to life, you would imagine that there would be a strong defence of the rights of people with a disability to live a full life, and to be protected.



- Alex Devine: I think what you do see in terms of the influence of the right to life is perhaps less access to abortion. There is a lot of discussion around that right to life issue when abortion comes up. Then people with disabilities feel particularly under threat in places like the Philippines and I do think in a country you are perhaps more likely to see children with Down Syndrome in a community as opposed to other areas where access to safe abortion or the Catholicism is an overlaid or-
- Ali Moore: But it doesn't translate to very strong enforcement of anti-discrimination legislation?
- Cathy Vaughn: No. There is a Magna Carta around the rights of people with disability in the Philippines. It's very high level legislation. There's a lot associated with the church. There's been a lot of organisations established often in quite rural areas that were set up as charities to support people with disability in the community and that's a positive thing to some degree. I think the challenges allowing those organisations the opportunity to mature and rather being a charitable model, having organisations that can develop to ones where people are advocating for themselves in a rights-based rather than charity based. We've worked with some fantastic disability advocates in the Philippines and a lot of the work we've done around violence and sexual and reproductive health has been about supporting those advocates or people who've got a lot of capacity in training around both their rights and the law and understanding about discrimination in the Philippines to then go and reach out to others who haven't those same opportunities.
- Cathy Vaughn: I think perhaps the most useful thing to come out of that long term research we've done in the Philippines has been the establishment of peer support groups for women with different types of impairments. A group of women who all have a hearing impairment, who are all deaf or hard of hearing supporting each other and knowing what their rights are and then supporting each other in actually seeking advice for a violent husband or seeking advice on how to access contraception and so on. They often go together and that lasts after the intervention because you've built a group that has solidarity who can stay in contact through social media and who many of those women have gone on to do really quite impressive things without outside intervention.
- Ali Moore: You're listening to Ear To Asia from Asia Institute at the University of Melbourne. I'm Ali Moore. I'm joined by engineer and social entrepreneur Huy Nguyen, Alex Devine from the Nossal Institute for Global Health and Dr. Cathy Vaughn who you were just listening to of the Melbourne School of Population and Global Health. We're talking about living with disabilities in Asian societies. Huy, in countries where even basic healthcare can be a challenge, what happens to people with a disability? Do they just slide down the scale of importance?



- Huy Nguyen: The sad reality is unfortunately yes. I've seen quite a few cases where people with disabilities literally are outcast from the community. There's a lack of understanding about that individual and it's even more challenging where people who don't have those family supports, that's the group that is most significantly challenged, even here in Australia as well. People who don't have advocates and we often have families on behalf. That's a sad reality. Even having access to basic health services, thinking about the reasons why whatever that be the case is around community and understanding and education, but I think it comes down to just not knowing how to support or help someone because people I think in general, we want to help each other and when we don't know how to support that individual, we generally kind of ignore it or leave it to someone else. Usually when people have complex disabilities, it's not because I think people we want to exclude or remove from our community, we just don't know how to support or help someone.
- Ali Moore: That obviously goes to education which we'll discuss further in a minute, but Alex, can I ask you about the link between poverty and disability?
- Alex Devine: Absolutely, and I think it's a link established early on in a persons' life. I think again if we go back to Cambodia, but we can use the same example from the Philippines. If a family has a child with a disability and the social support and the social security is not there, then that family may find it very difficult to continue working at the same level and therefore their income starts to drop. Also, therefore their capacity to care for their child with a disability starts to drop. That might then impact on that child's access to school and later their access to work. Throughout their course, they've got more costs, but not necessarily the resources to address that cost. We do again see that in Cambodia where they've done such an incredible job to reduce poverty rates across the country, but for families with a family member with a disability, the rates of poverty are significantly higher so 18% of families with a person with a disability still remain in poverty compared to 13% of families without a disability.
- Alex Devine: When you take into consideration the costs of disability, then that can go up to 35% whereas in Australia and I think this is maybe the purpose of the NDIS-
- Ali Moore: The National Disability Insurance Scheme.
- Alex Devine: The National Disability Insurance Scheme is to prevent families from incurring all the costs of disability. We also have much greater access to child care so parents can still work. We're also not relying on agriculture or change in agricultural landscape which is happening in Cambodia as well so families potentially would have been able to continue the sort of work that they were doing to bring in income whereas that is changing across Asia as



well.

- Huy Nguyen: Is that the cost of time taken away from a carer for someone with disabilities as some of the costs [crosstalk]?
- Alex Devine: So direct and indirect costs so it might be the costs associated with more costs to get the healthcare that you need. It might be that someone has a greater need for nutrition. It might be that someone needs greater heating, but also the time that it costs. Again, I think that's why in some contexts you see more children with disabilities, families finding it difficult to keep children with disabilities within that family unit which we know is the best thing for all children probably particularly for children with disabilities.
- Ali Moore: What about representation in broader society? Cathy, how well represented are people with disabilities in secondary education and also in the work force?
- Cathy Vaughn: Across the region, people with disability have lower levels of participation in the education sector and in the work force as they do in Australia. Particularly in the work force in Australia where we do poorly. It's a compounding issue. If you don't have access to education, then your employment opportunities are reduced and it's very difficult to try and catch up at the job seeking end of things when you haven't had access to basic primary school education or into secondary school or beyond. Then when people aren't in the work force or aren't in education, I think that reinforces prejudice and this is what I was talking about, the two sides of the same coin. If people are not visible in society, they're not seen as able to be in school, they're not visible in a work place. People aren't exposed to people with disability and realise, well, they're just like me, then it's difficult to overcome prejudice because people-
- Ali Moore: Because they're hidden away. Out of sight, out of mind.
- Cathy Vaughn: Yeah.
- Ali Moore: You made that point at the beginning of this conversation about the president whose daughter had a disability in Pakistan. Just what a difference a single role model can do to having the conversation and putting at the forefront of what's being talked about.
- Cathy Vaughn: Absolutely and we see that currently in the region where there will be people who through their own personal exposure to disability or of course acquiring a disability. Any of us who at the moment don't have a disability, could acquire a disability. It can really change your perspective on the position of people who've spent their whole life dealing with



communication barriers and physical access barriers and attitudinal barriers and that can make an enormous difference in a particular setting, but we shouldn't have to wait until someone has a child with a disability or acquires a disability themselves. We should all be able to recognise the intrinsic rights of all people including people with a disability.

Huy Nguyen:

Can I add an example onto what you told there about exposure to [inaudible]. I had a trip to China about two years ago and in one of the cities I was at, I was catching a train and to the side of my eye I can see this woman taking her camera out taking a sneaky photo of me. I quickly turned around and looked at her, she put it away and turned away. She's do that again. It didn't feel comfortable because for her in that situation, she's never seen someone even in a wheelchair who's travelling on a train by themselves in China and that's exactly what you're talking about is that just more exposure, more people out there to really start to get that across and even just a basic stuff like wheelchair and users. There's not that many that coming around. Just even that barrier just to go out because people's taking photos of you as well in that first instance.

Ali Moore:

How much of changing this is selling the benefits of integrating people with a disability into the work force and forget the human side of it, just do a straight cost-benefit analysis. Is that hard Cathy to sell the benefits?

Cathy Vaughn:

There are challenges because even the data on prevalence of disability in many countries is not there. Earlier on we were talking about under reporting and under representation. That's often because how disability is measured in a country is not done to the standards that it should be so if you just in a census ask the head of the household, "Is there someone with a disability in your house?", you get a very different answer than if you ask about activities. If you ask if someone has difficulty seeing or difficulty hearing or difficulty moving around, you'll get a very different prevalence and it is hard to argue to governments to invest if they think it's only one or two percent of the population. If they have the data to demonstrate that it's a much higher proportion of the population who has a disability, then there's a greater willingness. I think though the issue around the economic argument for investing in all members of the society is a really good one and we've seen it with increasing participation of women in the work force.

Cathy Vaughn:

Equally, we should be seeing it with increasing participation of people with disability and of course, recognising that for many, that's the same person. I think sometimes we talk about disability like it happens in a vacuum, but of course, people with disability are also women, they're men, they're people from ethnic minorities or religious minorities so this can be intersecting forms of discrimination that can prevent people having access to opportunities as well as disability.



- Ali Moore: Huy, if we can go back to something that you mentioned at the very outset, independence. How important is that and how difficult is it particularly in an Asian context to make people understand not how they think they should help, but how they should help?
- Huy Nguyen: Well, I think, in a way, it's quite challenging. Let me give an example of my recent trip to Vietnam. I'm fiercely independent. I want to do things myself. However, that kind of offends people as well when you're in country. They really want to help and they want to recognise as being helpful as well. When I was moving around, people insisted on carrying me around, move me, carry me upstairs, et cetera. They think it was absolutely quite fine, but when I say no, they get offended. For me to be able to communicate that from my perspective as an individual, sometimes I've got to give in just a bit and let people help. It's a little bit about pride, but I think it's how we in certain cultures, where being helpful is not a way where it's actually demeaning you as an individual person with a disability. It's both sides of the equation there.
- Ali Moore: Alex, we started this conversation talking about the numbers and talking about under reporting. To what extent has health research focused on disability?
- Alex Devine: I work in a health institute and we do have a disability unit, but I also have a number of colleagues that work in health systems and I do find that it's taken a number of years. We're definitely there now I think to convince them that disability is part of a health system as well and that people with a disability have the same right to health as people without disability. Then to make sure that when you are doing health research that you do include a lens of disability as well in terms of if you're identifying the barriers to health services in a country. You can't just do that for people that are able bodied, but you're also do need consider different types of challenges and different types of disabilities as well.
- Ali Moore: Cathy, does there need to be more research that actually involves people with a disability as opposed to does it round them?
- Cathy Vaughn: Absolutely and I think that's across all forms of health research. Sometimes there's certainly in our own research which was around sexual and reproductive health and violence, the work we were talking about earlier in the Philippines, we were specifically looking at the experiences of women with disabilities. A very large proportion of our research team were women with disability. There were women with disability interviewing other women with disability. We did a prevalence study. Half the team of the numerators going out and collecting data for the prevalence study were people with disability. They bring new insights into the data that you wouldn't get if you were just a research team that didn't have members



with disability in there. It totally enriched our analysis and changed the focus of some of our findings particularly in relation to sexual and reproductive health. I think it needs to be not just about research that's specifically about people with disability. For example, non communicable diseases which is a huge issue in the Asian region and growing. We know there's a strong link between some forms of disability and non communicable diseases.

Cathy Vaughn: Partly a non-communicable disease can be a cause of disability, if you have a stroke for example, but also if your diet is affected by poverty and that poverty is associated with disability or if your ability to exercise is being affected by impairments and that has an association with non communicable diseases, there's increasing evidence around the association between the two, but you don't see very many non communicable disease research projects that include team members with disability. I think that would be a huge step forward is if we, all forms of health research had an eye to inclusion, not just projects specifically about the experiences of people with disability or in the rehab sector which is where historically there's been perhaps ... I don't think there's actually been very inclusive research, but there's been more awareness that people with disability might need to use those services. I think it cuts across any form of health research. We should be including people with disability.

Alex Devine: And indeed, any form of research and the Australian government is now supporting that in terms of supporting the work that we do to build the capacity of all development researchers to include people with disabilities in their research they do. The other real benefit that has is that communities then see people with disabilities in positions of employment and positions of power. That can really change attitudes too.

Ali Moore: In fact, Huy, you've got a really interesting story about a friend of yours in Vietnam who runs a business. Tell us about the challenges that she faces?

Huy Nguyen: Yeah, so she is becoming quite successful. She has a quite high level of physical impairment, but now she owns and runs a business like a business, business where she employees other people with disabilities to take on digital projects, digital photo manipulation et cetera and in terms from recent other countries. We talk a lot. One of the biggest challenges that she had in her leadership role is being challenged internally as well where her own staff sort of sees her as someone with disabilities who in their perception may not have, because of her disabilities, may not have the qualities or the skills from just pure perception to lead them, the staff internally because of such an ingrained prejudice and all that kind of stuff even in her own team is what she tells me about one of the challenges which I think is very fascinating.



- Ali Moore: They're saying because you have a disability, we don't have to listen to you?
- Huy Nguyen: In a way, what credibility you bring and that's significantly challenging not just with all the external factors that she's really dealing with.
- Ali Moore: Coming off that, can I ask you especially when you travel around the region, how confident are you that the path to change whether that is on a more government infrastructure economic side or whether it is on those deep [inaudible] cultural traditions, do you think that path is becoming well trodden?
- Huy Nguyen: To change? To positive change? I think it is in a way especially more globalised connected world. When you have people with disabilities like myself travelling to other countries, people can see us around. I think where some of the exciting space that I think it's going to really happen is around more tourists who have disabilities that can travel around that have spending power, be able to go to places, be able to communicate with people and just listen and share their stories. I think that connected global world where we can now travel around and have the supports, I guess the ability to do that is one way forward, I guess, in terms of being able to have change happen and this big shift of movement right now which is my world around social entrepreneurship or social impact really taking things from a business perspective, a business lens. Business is really thinking and including and thinking about all this.
- Huy Nguyen: Any kind of business really because how cost cutting disability is how it impacts in all areas of our life and I think through entrepreneurship as a way to proceed with that. I guess my thing there is increasing number of globally connected communities sharing information, knowing what's out there, knowing the resources out there, travellers who have disability and that is another significant way as well as businesses moving forward especially social impact businesses.
- Ali Moore: Alex, are you optimistic?
- Alex Devine: I am optimistic and I think you have to be optimistic, but I do think that it requires ongoing advocacy and really continuing to shine the spot light on things that we can too across the region and it does require ongoing investment from the Australian government and other governments in the work that they do with countries across Asia and the Pacific. It does again require ongoing work with people with disabilities to identify the ongoing issues and what the solutions are. There's a long way to go, but there's absolute reason to be optimistic.
- Ali Moore: Cathy, I guess we're talking about it. That's a good thing.



- Cathy Vaughn: It's a good start. I think that like Alex, I'm optimistic. I'm very mindful of, that in this region, it's a region of incredibly rapid change. I'm very hopeful about locally driven solutions having visited for example the National Rehab Service in Korea and watching how Korean engineering and technology and ingenuity is being put to use in the disability sector. It's mind blowing. It's absolutely fantastic what they're doing there. I think that there are opportunities around the region with the rapid change that happens. As Huy said, to jump some of the steps that have happened in countries like Australia and leap-frog ahead. We have to be optimistic, recognising that there's still a long way to go.
- Ali Moore: A long way to go, but as you say, at least some progress has been made and some better analysis of the challenges. An enormous thank you to all of you for your insights. To Cathy and to Alex and to Huy, thank you very much for talking to Ear To Asia.
- Huy Nguyen: Thank you for your time.
- Cathy Vaughn: Thank you.
- Alex Devine: Thank you.
- Ali Moore: Our guests have been Dr. Cathy Vaughn of the Centre for Health Equity at the Melbourne School of Population and Global Health; Alex Devine from the Nossal Institute for Global Health, an engineer and social entrepreneur Huy Nguyen. Ear to Asia is brought to you by Asia Institute of the University of Melbourne, Australia. You can find more information about this and all our other episodes at the Asia Institute website. Be sure to keep up with every episode of Ear To Asia by following us on the Apple Podcast AP, Stitcher, Spotify or Sound Cloud. If you like the show, please rate and review it on Apple Podcast. Every positive review helps new listeners find the show and of course, let your friends know about us on social media. This episode was recorded on the 19th of July, 2019. Producers were Eric van Bommel and Kelvin Param of profactual.com. Ear To Asia is licenced under Creative Commons copyright 2019, the University of Melbourne. I'm Ali Moore. Thanks for your company.