

Shazana Mokhtar

Good morning. You're listening to the Breakfast Grille. I'm Shazana Mokhtar. 2024 marks 16 years since Malaysia signed the UN convention on the rights of persons with disabilities or CRPD with the provisions translated to local legislation via the Persons With Disabilities Act 2008. How much does the letter of the law and its implementation actually live up to the purpose and spirit of the convention? We're discussing these issues on the International Day of Persons with Disabilities with Murugeswaran Veerasamy, President of the Damai Disabled Person Association Malaysia and Meera Samanther, Co Chair of the Bar Council's Ad Hoc Committee on Persons with Disabilities. Muru, Meera, Good morning. Welcome to the Breakfast Grille.

Murugeswaran Veerasamy

Good morning Shazana.

Meera Samanther

Good morning.

Shazana Mokhtar

Now, Muru you lead the Damai Disabled Person Association, which alongside advocacy and awareness building also works to empower members of the disabled community to become independent and contributing members of society. So from your perspective, does the Persons With Disabilities Act, does it adequately promote the inclusion of disabled persons in public life?

Murugeswaran Veerasamy

I must say that you know, the government, obviously they have an intention to give some kind of protection for persons with disabilities that's living in Malaysia. At the moment, we have, if I'm not mistaken, it is not an official figure, but we have nearly about 740,000 people with disabilities registered. So I think it is a very, very good Act. But what person like me, you know, a lot of

activists, you know, feel that there is a room for improvement, you know, to make the Act more stronger and give us more rights here. So because of that, it's already been 16 years. As what you said, there is no amendment has been done. There is no changes has been done. Uh Just to let you know, in 2018, a group of activists, we did a big rally, you know, to actually ask the newly elected government that was under Tun Doctor Mahathir, asked the ministry where Dato' Seri Wan Aziza and Hannah Yeoh was the minister asked them to look at this Act again to do something about it. And because the pressure that we gave, they listened to us. And in December 2019, Hannah Yeoh have actually announced saying that they are forming a group called special project team for them to relook at this Act.

Shazana Mokhtar

And this is under the Ministry of Women, Family, and Community Development?

Murugeswaran Veerasamy

Yeah, in December 2019. And because of that, they already planning to do that. But poor thing, that government didn't last long. There was a change of government and because of that, there is delayed and the target was to actually table this Act in December 2020 to make the first amendment to the Act. But it doesn't happen.

Shazana Mokhtar

Meera, I want to bring you into this conversation because the law PWD was enacted prior to Malaysia ratifying the convention in 2010. The idea being that Malaysia only ratifies treaties that we're capable of implementing. So the PWD Act is meant to represent that implementation right? But it has been quite selective in terms of what it incorporates from the CRPD. What is missing in our local legislation? Where are we misaligned from the international standard?

Meera Samanther

You were very correct. The chronology of the way the PWD Act was drafted even before ratification. That's a very unusual step. But you ratify a convention, so you're making a global

commitment that persons with disabilities will have rights and they will be protected and their rights will be promoted. So that was a global commitment they made. So what we need is the Act to be in alignment, is harmonized with the convention. Now, your question is, what are misalignments? Plenty. I believe the Act is toothless because it has all its rights, but a person with disability cannot, if their rights are violated, they have no, they don't have redress mechanisms. There are no penalties. So I'll just go through it. It is important that the definition of disability must include, permit inclusion of other groups such as persons with dementia, other aging related disabilities, psychological disabilities. Now it is very limited to seven categories only. Only recently, rare diseases was included. There is no definition of discrimination and this is very clear in the convention. So if you don't have a definition of discrimination, how do you argue that there was discrimination? Remedies, you need to have remedies in the Act. So that when a person is affected by discrimination, you know what your remedies are and penalties for non compliance of the Act. The other is to include a mechanism for how do you enforce your rights? Court is quite adversarial and it's quite expensive with us. Lawyers can be expensive. This is where like in the sexual harassment legislation, they introduced the tribunal. Similarly, a tribunal to address these grievances, infringement of rights. And also we want the members of the tribunal who would be specialists in disability, persons who have lived in realities of it. You know, I think that is important just like in the SH sexual harassment tribunal members. The other gap that is missing in the legislation, the Disability Act, is we need an independent disability commission with powers to mainstream disability issues. So you know, it's all these ministries, they must have policies and guidelines to have disability inclusion. The other point I wanted to add is there are three conventions parked under the Ministry of Women Community Development: PWD, Children's Rights Convention, and women's rights, the CEDAW. These are three major conventions.

Shazana Mokhtar

All under one ministry?

Meera Samanther

All under one ministry. But mind you in relation to disability is parked under as a department under welfare. So it's like a subdivision. You know, disability, it's so it's a minefield and there are

so many different categories of disabilities. Can a department have that kind of power and human resources and financial resources to push forward for inclusive disability with all the ministries? Some of us feel that it should be parked under the ministry, Prime Minister's department, or a totally different ministry altogether.

Shazana Mokhtar

Muru you wanted to add to that?

Murugeswaran Veerasamy

We are parked under Kementerian Pembangunan Wanita, Keluarga Dan Masyarakat. There is no OKU there. We are parked under Masyarakat. In other words, they lie in line. Kementerian Pembangunan Wanita, Keluarga Dan Masyarakat, even though they have JP OKU, Jabatan Pembangunan Orang Kurang Upaya. But it's more to charity based than a rights based society. That is the actual scenario.

Meera Samanther

As I said, it's mind boggling. There are so many issues to deal with like Muru is involved in transport, accessibility. That itself not just transport but buildings then you have education, then you have employment, access to health, access to the criminal justice system. That is another minefield altogether because you need sign language interpreters, BIM interpreters. You need the police to be sensitized to whether the person, if the person is deaf, if he's apprehended, you put the cuffs behind his back and that is his tool for communication. You know, the judge must be sensitized to understand autism. So there must be, you know, this whole gamut of people that needs to be trained. It's not just the victim but the perpetrator, the witness, the judiciary, the interpreters.

Murugeswaran Veerasamy

Just to add on that. Maybe when I was reading in the, doing a research in 2017, I think UM student is actually have done a research. As to date, there is no legal action has been taken

using this Act to prove that, you know, this Act actually can actually help people with disability in case there is discrimination happen. But I also believe that the country at the moment, they are scared to actually give, remove the 41 and 42 is because they are not ready.

Shazana Mokhtar

Can you explain what Section 41 and 42 are about?

Murugeswaran Veerasamy

Section 41 is no action, prosecution, or other proceeding shall lie or be brought against the government, the minister, the council, any of the council and any of the members of the committee, and any other person lawfully acting on behalf of the council. That is 41.

Shazana Mokhtar

So no case can be brought against them?

Meera Samanther

Even if they acted in good faith. So it's called the ouster clause.

Murugeswaran Veerasamy

Right, and 42 is actually Public Authorities Protection Act 1948. That is another Act, you know, is give a certain level of protection against the government bodies.

Shazana Mokhtar

So that's a clear limitation of the Act. Essentially, they put these protections and rights in place. But you have no way, the disabled community has no way of actually holding those who are supposed to deliver those protections to account.

Murugeswaran Veerasamy

The federal government, the local government, they know that I believe, you know, because of that, if you open up and you, you remove this, they might think that, you know, they, they might be a number of legal actions against them. But at the same time, the people with disabilities are facing discrimination on our daily lives. When I come out from my house, you know, step out from the house to go to the nearest bus stop itself. I can name it. I can list down what are the discriminations are happening in my life on a daily basis. As you know, we have seven categories of people with disabilities, physical, blind, hearing impairment and many more. I think all of them when they step out from their house, they will have discrimination start from the doorstep as well. So these are the things that we need to look into. Maybe it's time, you know, we are, we are moving forward very rapidly to a developed nation. It's high time that the government relook at all these things, have engagement with the stakeholders to make sure that, you know, where they can come out with a win, win situation where we have to, you know,

Shazana Mokhtar

Level the playing field for all Malaysians. I'm speaking to Muru Veerasamy, President of the Damai Disabled Person Association Malaysia and Meera Samanther, Co chair of the Bar Council's Ad Hoc Committee on persons with Disabilities. We'll have more from this conversation after the break. Stay tuned. BFM 89.9.

Shazana Mokhtar

Thanks for staying tuned to the Breakfast Grille. Today is the International Day of Persons with Disabilities and joining me on the show to discuss themes related to the rights of the disabled is Meera Samanther Co-chair of the Bar Council's Ad Hoc Committee on Persons with Disabilities and Murugeswaran Veerasamy, President of the Damai Disabled Person Association Malaysia. Muru, I want to ask, you know, reforms, they require a strong push at the policy making and legislative levels. That means both government and parliament. Is this lack of urgency for the PWD Act to be reformed uh for perhaps um disability rights to be enshrined in the constitution. And we'll talk a little bit more about that. Is that lack of urgency related to the lack of representation of disabled people in these two avenues?

Murugeswaran Veerasamy

You see under the person with Disabilities Act, Akta Orang Kurang Upaya, there is a provision saying that 10 person has to be elected from the community, especially those who have experience, involved in advocacy movement so that there can be a voice in the national as a National Council members. But it's a bit disappointing that the current 10 people who are sitting there, eight of them are PHD holders and not a disabled person. Yeah, and you only have two person who is one blind and one hearing impaired to be there. Is there nothing about us without us is not apply for us to be there to voice out what we want? We don't want to be like a medical model with disability where people who are not disabled, who is telling us what to do, you know, that's another person.

Shazana Mokhtar

Ok. So like you said Muru, there has been a clear lack of involvement when it comes from the disabled community themselves. And so I'm looking then, what about among the broader MPs? Are there no MPs that take up, that champion this issue? And why, why do you think there's just that lack of interest perhaps on that part?

Murugeswaran Veerasamy

The issue here is when they are contesting on certain constituency, they definitely already have list of their voters. They already know how many percent of people with disabilities are living there. That's the number one. Number two, they also must look into the among the senior citizens are living in that area and they also must look into where there are people with mothers with pram and all these things are living in their constituency. The problem is now, they do not champion our right at the moment. I could clearly say here, in the parliament, you hardly hear them talking about us because they are focusing on more popular issues on that time so that you know, they become popular and they will be re-elected as a member of parliament or a member of Dewan Negeri (ADUN). You know, these are the things that are happening. That's why I propose. Maybe I think in India you have that, you know, they can amend a law to allow a reserve seats, reserved seat, only person with disabilities can contest that. Which means even though we are small in numbers, all political party here in that constituency, they only will put

people with disabilities to contest. You know, maybe they will understand us better to say something. Now we are fully depending on ministry of Kementerian Pembangunan Wanita, Keluarga Dan Masyarakat, for them to be our voice. But most of the time they only talk about we are giving free this, we are increasing this, we are setting up a center, you know, this kind of this kind of welfare thing. The focus to more, to make the person with disabilities to live life independent. I think there is a lot of lacking there. Not only from the federal government, but the local government, but we also must understand the local government actually have huge responsibility to make it happen. What they need to do is they need to sit down together with the federal government. They need to sit down with the local government. They need to sit down with the transport provider. They need to sit down with the developers. All these are, they should have a holistic approach in order for them to do something.

Shazana Mokhtar

Muru, isn't that what the National Council of Persons with Disabilities is supposed to do? It's established under the Act to be that main committee, right? That brings together all the different ministries like you mentioned the Transport Ministry, the local government ministry. So why haven't they been able to be that force?

Murugeswaran Veerasamy

See, I was in the national Council member for four years. Two terms yeah. The National Council members was chaired by the minister. You know, sometimes you call all the relevant representative from other ministers to come there also. Yes, they hear us. They listen to us. End of the day, the minister was the one decide what is the main priority to do. But when it comes to local government, you see like MPPJ, they used to have a councilor representing person with disability to speak on the OKU community behalf. I think the PJ is a very good example. You Know why? The late Anthony Thanasayan, you know, he was the first one to be elected as a council member in NPPJ. I think he have done a great job there. That's why you can see a lot of improvements that happening there in NPPJ because he's done the groundwork. But what about other local government? And we have 14 states in the country, you know, do we have representative to speak in their local meetings in the Datuk Bandar, who chair the meeting? Do we have the voices? Do you have the voices from majority of the categories, people with

disability that you have, to speak on our behalf. You know? I come back again under CRPD, the term is nothing about us without us. You know whether that is been fully implemented or not fully utilized or not. That is the biggest question here. If we are not there, definitely the need of person with disability will be sidelined and overlooked. Most of the time that happened.

Shazana Mokhtar

Meera, earlier, you mentioned about the Independent Commission that would be proposed under the amendments to the law. How would that be different from how the National Council operates now?

Meera Samanther

National Council meets four times a year.

Murugeswaran Veerasamy

Three times a year.

Meera Samanther

Sorry, three times a year. What can you do with three times a year? You know, so when we draft, redrafted the Act to the group of us, not the special task force, we were of the view that the National Council will look at policies within the Act. But when you talk about mainstreaming in disability issues, this is where the commission comes in. The commission, apart from mainstream disability issues, investigate discrimination, compel any person to appear before it and produce any document regarding disability related issues in an inquiry initiated by the commissioner, initiate action of its own for non compliance, and submit the report to parliament for review and debate and raise issues concerning PWDs. Because if you look at other countries like India has such a robust Act. Do you know they have a commissioner in every state? It's incredible how robust it is. They have the definition of discrimination as per CRPD. Not just India. South Korea, Thailand, Hong Kong, China is such a comprehensive definition of

discrimination, disability, and also they have a grievance mechanism, redress mechanism. The penalties are all stated quite clearly and they also have this term 'care partner'. It's mainly women who tend to take care. It's very gendered when it comes to care partner. I'm not using the word care giver, but we, I'm using the terminology care partner because both parties benefit from it, you know. So even in India, they have funding in the Act as a mandatory provision for national and state funds for persons with disability. So it's quite robust in our region. So in our country, we have nothing of it. We can't even have a redress mechanism. That's why since ratification, we have never ever submitted any report to the UN committee. The first two years after ratification, you have to file a, submit an initial report. After that, every four years, we've never appeared before the committee. Why? How do you go and appear before the UN committee and say, oh, this is the Act you have. You will be asked all the questions about where is the redress? Where's the penalty? Where's the definition? You are not, you have never harmonized your Act with the convention.

Murugeswaran Veerasamy

Yeah, even the convention on the right that we sign, we didn't sign the optional protocol. The optional protocol is actually giving us the stakeholders in Malaysia. Maybe you can write to the committee of the CRPD.

Meera Samanther

Optional protocol, you have to exhaust your remedies here before you go. So that is, we haven't even,

Shazana Mokhtar

We don't even have remedies in our country.

Meera Samanther

No point for me. My view is yes, I want the optional protocol as Muru so quite rightly said you know, but we want the Act first and we want our constitution amended because if the

constitution is the supreme law of the land, that's where our founding fathers come started it. If our constitution is not in alignment with or not harmonized with the uh with CRPD, what do we have? Are we enablers of discrimination? You know?

Shazana Mokhtar

So of course, you're referring to Article 8 of the constitution, you know, which sets out that all Malaysians are equal, but also specifies that there are certain categories in which discrimination is prohibited. Disability is not in that category.

Meera Samanther

And neither is it in Article 12, in terms of education. It says in terms of education, Article 12, you cannot be discriminated on the grounds of race, religion, but disability is missing.

Shazana Mokhtar

Meera, What are some of the arguments that you've heard objecting against the inclusion of disability under Article 8 of the constitution? Where is the pushback coming from or is this just something that people don't think about?

Meera Samanther

I have not heard any arguments against it yet. Maybe because it's not in their radar. Unless they say, oh, we have Article 8, all persons are equal, you know, but no, that's not good enough. You have Article 8 too. Why did you then include all these categories of gender, race and religion? What was the whole purpose? You know, we want our supreme law of the land to be in tune, to be aligned, to be harmonized with the convention.

Shazana Mokhtar

That really sets the tone for what happens across the country in terms of our top policy, right? I'm speaking to Muru Veerasamy of the Damai Disabled Association and Meera Samanther from

the Bar Council on an extended edition of the Breakfast Grille to mark the International Day of Persons with Disabilities. After the 8:30 a.m. news bulletin, we'll continue the conversation and look at societal attitudes within and towards the disabled community. BFM 89.9.

Shazana Mokhtar

You're listening to an extended edition of the Breakfast Grille in honor of the International Day of Persons with Disabilities. With me on the show today are Murugeswaran Veerasamy, President of the Damai Disabled Person Association and Meera Samanther, Co Chair of the Bar Council's Ad Hoc Committee on Persons with Disabilities. Muru, we've been talking a lot about how there just isn't representation of the disabled community at decision making levels, whether it's at local government or parliament or even top levels of government. How do we do better then in amplifying the voices of leadership of persons with disabilities? Where I think you've given some suggestions in terms of uh tweaking the representation in parliament for example. Apart from that, where do you think we can provide better support for the perspectives of disabled people to be acknowledged and actually acted upon?

Murugeswaran Veerasamy

I believe that, you know, in order for the disabled themselves to be the voice to aggressively push for the changes, they have to have some knowledge. What is the right that you have for them to do that? They need to go to school. If you don't have the basic education that you need, sometimes, you know, for them to survive itself is the problem. When it is the situation where survive is that a problem, they won't look into all this, you know right base and they also won't volunteer themselves to actually push for it. So I believe that, you know, it must come from the beginning itself, you know, the school, primary school must be accessible, the secondary should be accessible, the universities should be accessible, the workplace should be accessible. But I would openly saying that, you know, that is lacking among people with disabilities where we need more people to come in. You, you need to mix, you know, just because you are a disabled person, you only meet another disabled person. You know, you talk on your friends, everything is a disabled person means then you won't learn anything. You need to able to mix around with everybody. Like people like, you know, who have legal knowledge, people who are attend to the

meeting and the ministry level, local government level, you must get involved. It's quite lacking on our side also.

Shazana Mokhtar

But I suppose we also have to acknowledge the lack of opportunities that disabled people have perhaps. It involves them to come out and be brave, but is the public itself accepting of including them in? And I wonder if there are certain attitudes or mindsets that need to be changed from the public side in order for true inclusion of the disabled community to happen, not just relying on the disabled to push themselves in.

Meera Samanther

One of the biggest barrier, cultural attitudes and institutionalized barrier. You know, like Muru was just speaking about, you know, if you want to get into employment, you must have access to education. And then even if you get into employment, you must have in the private sector or even the government sector, reasonable accommodation to be able to provide. Like how in here you provided the ramp for Muru to come up to the studio. You know, those are pertinent questions we have to ask whether there's reasonable accommodation or not, if not, you're not providing access and you are limiting the rights. So it's a chicken and egg problem. You know, you talk about employment, oh we've given 1% employment, please, the 15% of persons with disability. And even university that Muru was talking about, we have cases of a person, as soon as they apply for public university, the kind of subjects you can apply of courses is limited. You tend to get community college. So that is institutional barrier.

Murugeswaran Veerasamy

That is what we've been championing actually. Damai, we actually focus on the ability more than the disability. If you have, let's say one hand is no more and you have only have one hand, we try to ask them to focus on what you have. The ability that you have for you to live life independently. You know, and Meera rightly touched on the 1% job opportunity for people with disabilities. It's been there since 1980's. And what I read was, you know, a report from Malaysian, there is one agency actually, they have come out with research, you know, in 2023

where only 12,000 of people with disabilities are employed if you compare to, you know, how many numbers are registered. So that is a very low numbers, you see. Yeah. And also the welfarism part when you are falls under the B40 category, of course, the government give you a lot of help. They give you monthly allowances, you get 450 monthly and some of the organization get government funding, you know, yearly for them to survive. So when all these things are happening, they are solely depending on government help for them to survive on day to day basis. Sometimes they don't speak out, you know. They want to be protective. They scared that, you know, their rights will be removed. You know, that's another part, you know, we need to look into.

Meera Samanther

Don't get us wrong. I think a lot of PWDs do need the welfare until you can have access, then it can be leveled to a certain extent. But you must enable them to access their rights and live independently, have autonomy to make decisions in their own. You know.

Murugeswaran Veerasamy

For example, when I was in overseas, I can actually get up in the morning and get ready, push my wheelchair, go to the nearest bus stop, take a bus, go to the anywhere that I want and after the meeting or anything, I can go to point A, point B, point C all by myself without depending on anybody. If you can have that kind of a level field, we can see people with disability will go out. Why they want to settle with the small amount of money that you have? You know, you can actually go for more. Why that kind of mindset, mentality is not among the majority of PWDs is because they feel that it's a bit of hurdle in every day's life for them to go out there. They have to go through a lot of challenges for them to.

Meera Samanther

But you see, we've been talking a lot about visible disability, but there's also invisible disability and a lot of the whole community is unaware of, I mean, it is what you call hidden disabilities. Yeah, it's like chronic illness, learning disability, autism spectrum disorders, asthma, chronic fatigue, mental illness. And these hidden disabilities, the community does not know, and they

should be, also be able to have access and that's where the community needs to be sensitized. Not just the community, it is the ministries must be made aware of this hidden disabilities. You know.

Shazana Mokhtar

It's so challenging because they're already behind on the physical disability aspect, right? But that's the uphill battle that is being tackled at the moment. All right, in the little bit of time that we have, what would be your top calls to action on this International Day of Persons with Disabilities. We've talked at length and I know that list is very, very long. But if you could summarize that into your final message for this day.

Murugeswaran Veerasamy

I want to celebrate this day. And of course, we are not bad. We have, the governments are listening to us from the day I've involved in this disability movement until today. A lot of improvement has taken place, especially the Ministry of Transport. I think they are doing a great job. You know, they, you can see, you know, the LRT, MRT, KTM and I'm actually one of the Ahli Jawatan Kuasa under MOT and they are listening. They are engaging. In fact, we do a lot of audits, you know. Throughout the country, improvements are happening on the Ministry of Transportation level. But this is not only involve Ministry of Transport. You need to have the support of Kementerian, kerajaan KPKT where the infrastructure barriers are also not there. And also we need to have support from all other ministers as well. So that ,you know, holistically, you can actually make things happen so that people with disabilities in this country can live life independently. Of course, we are here as a citizen of this country and OKU person for nearly 36 years. I want to see this country, this land is equal for everybody and accessible for everybody. That's my call.

Shazana Mokhtar

Thank you so much, Muru. Meera, what about you?

Meera Samanther

Mine is the most important thing is, first, amend the constitution, you know, as Muru says, you know, transport here. It's piecemeal, you know, is being done. I mean fantastic Transport, Ministry of Transport is looking into it, but we have to start with the Supreme law of the land to be amended. That is one. Article 8(2) and Article 12, we need an Act amended. That is the most important thing. If not, if it is violated, if in how do you get redress mechanism and all local legislations, Education Act, Transport Act, must be in alignment with the PWD, which will be in alignment with CRPD. So, for that to happen, Constitution and the Persons with Disability Act together with other legislations must be in alignment with, harmonized with CRPD. Only then can we say that we have a legitimate seat in the Human Rights Council that we have now. Then please, I don't know how we can even sit in the Human Rights Council and say we are providing human rights and liberties, promoting protection for persons with disabilities.

Shazana Mokhtar

Meera, Muru. Thank you very much both for this very important conversation and a lot of insights on how we can all do better when it comes to persons with disabilities. Thank you so much for joining me today.

Murugeswaran Veerasamy

Thank you BFM.

Meera Samanther

Thank you so much Shazana.

Shazana Mokhtar

I've been speaking to Murugeswaran Veerasamy, President of the Damai Disabled Person Association Malaysia and Meera Samanther, Co Chair of the Bar Council's Ad Hoc Committee on Persons with Disabilities. This has been the Breakfast Grille on BFM 89.9.