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UN Human Rights Council

Submission by The Leprosy Mission Papua New Guinea and the International Federation of Anti-Leprosy Associations (ILEP) in collaboration with the PNG Disability Sector Coalition (DSC) and the PNG Assembly of Disabled Persons (ADP).

Submitting organisations

The Leprosy Mission Papua New Guinea (TLM)

The Leprosy Mission (TLM) works across PNG to support people affected by leprosy. We are a part of The Leprosy Mission International, which is the largest and oldest leprosy-focused organisation in the world, having been founded in 1874. Our work in PNG includes support of the National Department of Health in leprosy awareness raising, training of Health Workers in leprosy, managing leprosy cases throughout the country, providing leprosy-related disability self-care, as well as providing education opportunities and livelihoods training. TLM has consultative status with ECOSOC. Address (for PNG office): Unit 7, Wapil Crest Apartments, Budoa St, East Boroko 111, National Capital District, PNG. Website (TLM International): www.leprosymission.org. Email: timpng2016@gmail.com.

International Federation of Anti-Leprosy Associations (ILEP)

The International Federation of Anti-Leprosy Associations (ILEP), founded in 1966, is a federation of 13 member associations working in leprosy-related activities in 63 countries. Its goal is zero leprosy, including zero stigma and discrimination against persons affected by leprosy and their family members. Persons affected by leprosy play a significant role in organisational decisions through the operation of a high-profile Advisory Panel and through interaction with country-based people's organisations. ILEP has consultative status with ECOSOC. Address: Route du Nant-d'avril 150, 1217 Meyrin, Switzerland. Website: www.ilepfederation.org. Email officer@ilepfederation.org.

PNG Assembly of Disabled Persons (PNG ADP)

Founded in 2002, PNG ADP advocates for the rights of persons with disabilities, builds capacity for DPOs that are members of PNG ADP, and works throughout the Disability Inclusive Development space. PNG ADP does not have ECOSOC consultative status. The Program Manager is Ross Tito, email rosstito143@gmail.com. Address: PO Box 4364, Boroko, National Capital District. Telephone: (+675) 79435457. Email: pngadp@gmail.com.

PNG Disability Sector Coalition (PNG DSC)

Founded in 1979, the PNG DSC is an NGO and is pillar two in the National Policy on Disability 2015-2025 implementing structure. Its main activities include coordinating and keeping a registry of all disability service providers across PNG, advocating and promoting the human rights of persons with disability, creating the platform for disability service providers through workshops and conferences, and participating in national policy development. PNG DSC does not have ECOSOC consultative status. The interim chair is Ben Theodore, Email: bentheodore46@gmail.com. Address: Section 477, Allotment 10, Talport Road, PO Box 353, Vision City, National Capital District. Telephone: 74592526/70228262.

Universal Periodic Review, Papua New Guinea, 2021: Joint Submission on the rights of persons with disability and persons affected by leprosy within PNG

1. Background

The issue of leprosy has never been mentioned in the reports of the Universal Periodic Review for PNG, but it is an issue that requires attention. This consortium met several times to discuss the process of the submission, go through the previous recommendations, and research and compile examples and information in relation to various disability rights. As this submission demonstrates, people affected by leprosy and disability in PNG are amongst the most marginalised in the country. They regularly face discrimination and are denied access to their human rights.

WHO data suggests that there have been between 500 and 600 people diagnosed with leprosy within PNG each year since the last Universal Periodic review of this country. From 1994 to 2019, there were 10,898 leprosy cases diagnosed in PNG. Of these, 3,329 were children (less than 15 years of age), and 1,089 were cases that already had visible disability at the time of diagnosis. There are thousands of people living with leprosy in PNG and, as this report will establish, their human rights are not being respected.

Leprosy is a mildly infectious disease and is treatable with multi-drug therapy treatment. However, despite the fact that leprosy is easily treatable, there remains substantial stigma and fear surrounding people affected by leprosy in PNG. Because of this prevailing stigma, leprosy has become far more than just a disease; it has become a profound human rights issue. As this submission demonstrates, a leprosy diagnosis often means that a person will have their human rights breached and abused.

Persons with disability face discrimination and stigma in PNG. Rates of disability vary across PNG; in urban areas the rates are around 10 percent, but in rural areas the numbers can be closer to 23 percent due to heavy physical work.¹ Supernatural causes, such as sorcery or evil spirits, are sadly still reported as a perceived cause of both disability and leprosy, more commonly in the rural regions. Accessing your rights as a person with disabilities in PNG is far from easy. Further, persons who are affected by leprosy-related disabilities face intersecting, double or even triple discrimination (based on their gender and age).

Papua New Guinea ratified the *UN Convention on the Rights of Persons with Disabilities (CRPD)* in September 2013. Despite this, people with disabilities and those affected by leprosy are denied their human rights on a daily basis.

2. Access to justice

The Leprosy Mission has witnessed many instances when people with disabilities and those affected by leprosy are denied access to community life. We have spoken to Anita* She comes from Enga Province and is a 36-year-old mother of two children. She walks with the aid of elbow crutches. She encounters discrimination daily. She struggles to access public transport, offices, commercial buildings, and public buildings (contravening CRPD Article 9). Other parents and teachers stare at her when she drops her children at school. When Anita gave birth to her first daughter, no reasonable accommodation was made to allow her to be safe and comfortable during her hospital stay. She was placed in a room that was far from the bathroom and was not allowed to have her guardian with her for support. Anita once applied for a job in

the private sector and was invited to interview, but when she arrived at her interview on crutches, the business immediately sent her away (Contravening CRPD Article 27).

During its UPR in 2011, PNG informed that a National Human Rights Institution (NHRI) would be operational by 2012. During the UPR in 2016 the NHRI was still not in place. In 2021, there still is no NHRI in PNG, so Anita and other persons with disabilities who are denied their human rights have no platform to raise their complaints.

People with disabilities and leprosy too often cannot go to the police for support on systemic disability rights violations. They are ignored, dismissed, and rejected by the police and judicial system. The Human Rights Watch report 2020 notes that police abuse and corruption is a serious issue throughout PNG.² This negative approach was the experience of Rita*. Rita has Down Syndrome and was sexually abused by a male relative at their family home. The matter was reported to the police, but they were unable to conduct an interview with the victim because they were not trained to communicate with her.

Betty* struggled with similar difficulties within the justice system. Betty was born deaf and in 2004, two prison escapees raped her when she was alone working in the garden. She suffered serious spinal injuries in the attack that left her relatives caring for her full time. Her case was reported to the police and her attackers were caught, but the Courts could not proceed because of communication difficulties with the victim.

The justice system in Papua New Guinea is not equipped to support many persons with disabilities and the lack of a National Human Rights Institution leaves those facing injustice with nowhere else to turn.

Our recommendations

- 2.i. Following UPR recommendations in 2011 and 2016, the PNG Government should immediately begin developing a National Human Rights Institution according to the Paris Principles. This NHRI should be developed and be running effectively before the next Universal Periodic Review of PNG. Once this NHRI is running, those who have experienced disability-related discrimination within PNG will be able to have their voices heard.
 - 2.ii. PNG has yet to pass comprehensive disability legislation. The PNG government should pass the draft Disability Bill that has been under development since 2018. It is important that the PNG Government shows its commitment to this legislation and, more importantly, to its implementation.
 - 2.iii. The Government should work harder to ensure that the CRPD is being implemented properly and the violations of the Convention are addressed.
 - 2.iv. Disability Inclusion and Human Rights should be a compulsory subject in all Law and Justice training. This will limit the number of persons with disability who are not receiving adequate support from the judicial system.
- 3. Protecting and promoting the human rights of persons with disabilities in all policies and programmes**

Under the General Obligations of Article 4 of the CRPD, States must protect and promote the human rights of persons with disabilities in all policies and programmes. Papua New Guinea's Vision 2050 document is a guide for the future of this nation,

while the Medium Term Development Plan III (2018-2022) is a crucial strategy to guide how the government serves its citizens.

The Vision 2050 document states that *'People should be empowered, their rights recognised, and they should be included in mainstream and economic life.'* The Medium Term Development Plan III states that *'rights-based approaches must be promoted to provide the same opportunities to people with disability as ordinary people in education, health services, employment, and others.'*

These are commendable notions and we applaud them. However, Anita's experiences tells a different story. Anita has faced discrimination and has been treated differently because she is a woman with a disability. Discrimination against people with disability and leprosy is not mentioned in the Discriminatory Practices Act 1963. So while the national plans do recognise the importance of protecting and promoting the human rights of persons with disabilities, the implementation of this premise is currently lacking, with no law against such discrimination. In addition, none of the three significant Government Departments (Community Development, Health, and Education) have committed to act on the Assistive Technology Guidelines 2016, which facilitate the empowerment of and opportunities for persons with disability.

Our recommendations

- 3.i. The Discriminatory Practices Act 1963 should be reviewed and updated to include discrimination against people with disability, leprosy, those accused of sorcery, and all other forms of modern discriminatory practices.
 - 3.ii. The Government should appoint a **Vision 2050 Disability Champion** to be responsible for ensuring that Vision 2050 programmes of action ensure access to and mainstreaming of disability rights. The Disability Champion should have regular consultations with civil society and organisations of persons with disabilities so that the latest issues are addressed. This Disability Champion should have the necessary resources to achieve effective monitoring. Vision 2050 must lead to real change.
 - 3.iii. The Government should be deliberate about including the voices of persons with disability in the development of the Medium Term Development Plan IV (2023-2027). This next plan should include actionable and achievable measures, including those given in the Assistive Technology Guidelines 2016, that will improve the lives of persons with disability and persons affected by leprosy, according to the recommendations from the consultation phase.
4. **Equal recognition before the law for people diagnosed with leprosy**
The PNG Government's 'Suppression of Leprosy Ordinance 1923' currently places persons affected by leprosy at risk of legal discrimination. The Ordinance was established by Australians, but it has never been repealed. The Ordinance allows persons affected by leprosy to be called 'Leper' and be confined to 'leper stations'. It also states that any person who conceals or secretes any persons affected with leprosy who is living in confinement (to avoid going to a 'leper station') will be guilty of an offence.

This Ordinance is based on out-dated and scientifically incorrect beliefs about and attitudes towards leprosy. Leprosy is only mildly infectious and anyone who has leprosy can be safely treated as an out-patient while living and working in the

community. Leprosy has been curable since the 1950s and the current WHO endorsed multi-drug therapy has been used globally since the 1980s. The Ordinance is wholly unjust and codifies into law the misguided and cruel assumption that persons affected by leprosy are second-class citizens.

Our recommendations

4.i. The Government should repeal the *Suppression of Leprosy Ordinance 1923*. We recognise that this piece of legislation is old and outdated and so it is easy to forget about its existence. However, while it remains on the statute books of PNG, it allows persons affected by leprosy to face legal discrimination and removes from them their human rights. This sends a horrible message to the thousands of people affected by leprosy across the country and undermines our efforts to demonstrate to the wider - and often suspicious - public that no one should face discrimination because of leprosy.

5. Women with disabilities

Women with disabilities experience gender discrimination as well as disabling barriers. Sadly, more than two thirds of women in PNG are victims of domestic violence. Women and girls with disability and/or leprosy are triply discriminated and particularly targeted by perpetrators of violence because of social exclusion, limited mobility, a lack of support structures, communication barriers, negative social perceptions and powerlessness.

PNG ratified the CEDAW in 1995, and has laws in place to protect women and children, including the Lukautim Pikinini (Child Welfare) Act 2015 and the Family Protection Act 2013, but they are rarely enforced. Initiatives such as Family, Sexual, and Violence Units within the police force remain limited, with police themselves targeting children and adults for sexual violence. A lack of services for victims requiring assistance compounds the problem. Not enough is being done to support all women, especially the most vulnerable of women in PNG.

There are serious cultural and institutional issues that are causing gender-based violence to be as widespread and devastating as it currently is in PNG. There will be submissions by Women's Rights groups that will be better placed to address these underlying issues. Our wish, as a consortium focused on disability and leprosy, is to ensure the Government recognises the multiple discrimination that women and girls with disabilities and leprosy face when they are encountering gender-based violence.

Our recommendations

5.i. Any Government-based interventions to tackle gender-based violence should include perspectives from women with disabilities and leprosy so that these interventions will not forget their specific needs. Often their experiences of gender-based violence are even more horrific than those you hear from the wider female population. Their voices must be heard and they must be included in all related interventions.

6. Right to Education

We know that children with disabilities are far less likely to attend school than those children who do not have disabilities³. We also know that children affected by leprosy (3,329 over the years since 1994) are more likely to be turned away from school

because of stigma and fear surrounding the disease, or are likely to miss school due to ongoing illness caused by leprosy.

Paul's* experience is typical of children with disabilities in PNG. He had been attending school along with his peers until he developed Guillain Barre Syndrome (GBS). Following the development of GBS, Paul was unable to stand or walk independently and came to rely heavily on his parents. The school did not offer him extra support so he was no longer able to attend classes. Following treatment and rehabilitation he is able to move around without his parents, and he has re-enrolled in school. However, even upon re-enrolling, Paul has experienced discrimination due to his disability and has required extra attention from an Inclusive Education teacher.

Our recommendations

- 6.i. The PNG Government should provide more training and resources (including assistive technology) to schools and teachers so they are better equipped to cater to the needs of children with disability and children affected by leprosy. They should approach Civil Society and organisations of persons with disability to seek support in developing resources that will best equip schools to challenge discrimination in the classroom and welcome pupils with disabilities back, so they can participate and feel included.
- 6.ii. The Government should, in the period leading up to the next UPR, begin collecting comprehensive data that details the school attendance rates of children with disabilities and children affected by leprosy. Using this data, coupled with increased resources and training for schools, they should aim to improve attendance rates year on year, so that fewer and fewer children miss out on their education due to a medical diagnosis. When PNG next undergoes the UPR process, they will be able to demonstrate the improved numbers of children with disabilities and leprosy attending school.
- 6.iii. The Government should immediately increase funding for institutions that are delivering academic courses and training workshops for mainstream and specialist teachers of children with disabilities in order to support the achievement of recommendation 6.ii.

7. Access to health

In a country of nine million people spread across 462,840 km² of land, there are only a few rehabilitation centres that persons with disability can access. This is indicative of the seriousness with which a person with a disability's right to health is taken in PNG. The lowest estimates of disability rates in PNG are around 10 percent, which means that at least 900,000 people must share access to these few rehabilitation centres. Further to this, these centres are of little use to many persons with disability, particularly those who struggle to access public transport, those who live in rural and remote areas, and those who do not have the means to pay for transport. An Australian funded research project in 2015 estimated that just two per cent of PNG's people with disabilities receive government services⁴. Under these circumstances, a huge percentage of PNG's disabled population cannot access their right to health and rehabilitation.

A further indication of the issues persons with disability and persons affected by leprosy face when accessing their right to health in PNG, can be found in their experience of the Covid-19 pandemic. The Government's handling of the pandemic

has regularly caused alarm for persons with disability. Government briefings on the pandemic have taken place without assistive technology (sign-language interpretation and guidance provided in braille), and the questions that are specific to disabled groups have been ignored by the Government. Ross Tito the Executive Officer of PNG Assembly of Disabled Persons said,

*'...a wheelchair person will need the help of another person so if you are practicing social distancing of one meter that would not work... and let alone a person who has no elbow trying to cough into another elbow...'*⁵

There is also the experience of women giving birth that we must consider. Under section 2 of the report we heard about the experience of Anita, who was treated very poorly by a nurse when she was giving birth to her first daughter. She was placed as far away from the toilets as possible and the guardian that she needed with her was sent away. Other women with disabilities have been told to their faces that they should not be having children. The conclusion we come to from Anita's and these other women's experiences of maternal health services across the country, are that they are not fit for use for persons with disability.

We also recognise that the right to health is not limited to physical health, but includes mental health, as well. According to the World Mental Health Survey from 2004, it can be estimated that 13 percent of a country's adult population will experience a mental disorder over their lifetime, of which 10 percent will experience a moderate to mild form of mental illness and 3 percent will have a serious mental illness. When these percentages are applied to Papua New Guinea's current adult population (over age 15), we can estimate that 547,170 adults will experience a mental health disorder during their lifetime, and 126,270 adults will experience a severe form of mental illness. Despite these figures, and the presence of the Mental Health Act 2015, access to mental health services is limited, and many people with psychosocial disabilities and their families often consider traditional healers to be their only option.

Our recommendations

- 7.i. The Government should provide double the number of disability rehabilitation centres (equipped with assistive technology) in PNG, in addition to promoting Community-Based Rehabilitation in rural areas through local NGO partnership, ahead of the next Universal Periodic Review.
- 7.ii. The Ministry of Health should speak directly to Civil Society and organisations of persons with disability during national emergencies, such as Covid-19. Through speaking to these groups, the Ministries can ensure that everyone can access the information they need to stay safe and healthy.
- 7.iii. The Ministry of Health should speak to Civil Society and organisations of persons with disability in combination with those responsible for maternal health services. Together, these groups should begin the process of improving the experience of persons with disability when accessing these services.
- 7.iv. All midwives, nurses, and other healthcare professionals working within maternal health services should also be provided with training and information that will equip them to provide the best possible care for persons with disability and leprosy.

- 7.v. The Ministry of Health should hold the public accountable to the Mental Health Act 2015, and begin the process of scaling up mental health services within the country. By working in partnership with Civil Society, they can make plans to better care for this woefully underserved population within PNG and raise awareness about mental illness, which will reduce stigma.

8. Access to employment

Access to employment is a complex issue in PNG. Many persons across the country are struggling to earn a living because they have not received the right training and resources. Disability and leprosy add unwanted complications to that process.

The story of Mark* is an example of how disability can cost a person their job in PNG. Mark was a security officer employed by Bank South Pacific. Whilst at work he was ambushed and shot. The attack left him blind. The bank paid him K18,000 and discontinued his employment because of his impairment. BSP failed to support his claims to Worker's compensation and because he could not access legal aid, Mark has been living without compensation for 15 years. He has struggled to provide for his family.

Earlier in this report, we shared the story of Anita, who was turned away from a job interview because she uses crutches. Later in the report we will share John's* story. John was starting his medical studies when his university told him he could not be a doctor because he uses a wheelchair. Now John is studying to be a lawyer.

A key element of The Leprosy Mission PNG's operations is working with vulnerable groups to ensure they have the skills and resources they need to access a sustainable livelihood. Whilst we are glad that we have been able to help these individuals, families, and communities, we also recognise that the Government of PNG has to do more to ensure that vulnerable people - especially those living with disability or leprosy - are not left without access to a sustainable livelihood. The consistent provision of appropriate and high quality business knowledge and assistive technology will be paid in return by the achievement of higher levels of education and training. More people with disabilities will be in employment, and able to conduct small or medium size businesses. It is quite simply sound economics.

Our recommendations

- 8.i. The Government should work across relevant Ministries to consider and implement the suggestions in Humanity and Inclusion's guide to inclusive and sustainable livelihoods⁶.
- 8.ii. The Government should reach out to the groups who have submitted this report so that we can work together to scale up the livelihoods work that we have been developing over many years. We ask the Government to begin this process of dialogue with us before the end of 2021. Together we have the tools to make sustainable livelihoods possible across PNG.
- 8.iii. The Government should work with employers in PNG to change perspectives around what persons with disability and persons affected by leprosy can contribute to the workplace. There is a wealth of information and case studies that demonstrate how persons living with disability due to leprosy have become key members of their work place and have led the way as self-employed entrepreneurs. In accordance with Section 11 of this report

(Awareness-raising), we believe that a change in societal attitudes will help people with disabilities and leprosy to access sustainable livelihoods.

9. Participation in cultural, social and political life

The Vision 2050 report notes that the Government will, *'Prepare provision for reserve seats for disabled and other sizeable marginalised segments of the population [within the National Parliament]'*.

Our recommendation

- 9.i. The Government should outline what it is doing to fulfil the Vision 2050 aim of preparing seats within parliament for persons with disability. Civil Society and organisations of persons with disability would gladly work with the Government to make this part of our national vision a reality.

10. Accessibility

One of the common themes that is crosscutting throughout this report is the issue of accessibility. Article 9 of the CRPD talks about providing access to life through appropriate facilities within buildings, through providing information in mediums that are accessible to persons with disabilities, and to provide training for stakeholders on these issues.

Despite this, we have heard that Anita was left far away from the toilet when she was in hospital to give birth. Anita also told us that accessing public transport in Port Moresby is a constant struggle for her. We also know of the story of a woman called Julie, an amputee, who cannot access markets because there is no accessibility ramp for her. Julie also said about her experience in hospital, *'There are times when I crawl with my hands to the (hospital) toilet - I try my best because I need to help myself'*⁷.

In section 11 of this report we speak of John's experience trying to study medicine at the University of PNG. One of the challenges he faced, despite being a wheelchair user, was that John was offered accommodation on the third floor of the student building, that was only accessible by stairs. Furthermore, we have heard about the lack of disability support and inclusion that was provided by the Government when sharing crucial information about Covid-19. As well, people affected by leprosy face barriers of fear, discrimination and rejection.

The lived experience of persons with disability and leprosy in PNG is that in every part of the country they encounter places, people, and information that they cannot access, because they have not received the support that the CRPD calls for them to receive. The support needed has already been outlined in the National Policy on Disability (NPD) 2015-2025's Finance and Budget Framework. To date, the Government has not delivered on its promised annual budget of PGK four million to facilitate the implementation of the NPD.

Our recommendations

- 10.i. The Government should assess all Government buildings to ensure they are accessible for persons with disability.
- 10.ii. The Government should ensure that all Government staff are given the appropriate training they need to care for persons with disability.
- 10.iii. The Government should speak to Civil Society and organisations of persons with disability to discover the greatest challenges of access (whether

environmental, institutional or attitudinal) for persons with leprosy and disability across the country. These groups should work in partnership to develop a pathway forward.

- 10.iv. The Government should annually budget for implementation of the NPD and immediately provide funding for one or more NGOs to partner with Government on the provision of Assistive Technology to people in PNG.

11. Awareness-raising

As we have seen throughout the entirety of this report, attitudes surrounding disability and leprosy in PNG are a serious problem. We can take, for example, the story of a man who wanted to be known as John. John uses a wheelchair and had to overcome various accessibility challenges to graduate from secondary school. When he graduated, he was selected to study a Bachelors in Medicine at the University of PNG. He was enrolled at his foundation year at Waigani UPNG Campus, but when he came to enrol for his second year, he needed to enrol at Port Moresby campus. When he arrived for enrolment, the administration of the medical campus refused to enrol him. They said that he would not be able to serve patients properly if he is in a wheelchair. They advised him to study law or accounting instead. After trying to push his case forward, John eventually decided to study law. Now in his fourth year of law school, John wants to become a lawyer who will fight and advocate for persons with disability.

We also know that discrimination is a reality for many persons affected by leprosy in PNG. We know the story of Stanley*, who was diagnosed with leprosy and faced discrimination from his community. Thankfully, he was able to seek comfort from his family. There is also the story of Thea*, who was diagnosed with leprosy when she was a schoolgirl. She told us this:

“Because of my leprosy I felt shy around my friends at school. When I found out I had leprosy I completely stopped going to school. My friends stopped asking about me. When I saw my classmates in my community, I tried to hide from them. I was haunted by how they would tease me, so I avoided them altogether.”

So many of the people we have talked about throughout this report have faced challenges because of the stigma that faced them as persons with disabilities and persons affected by leprosy. That this should be such a routine occurrence for all of them is painful. It suggests that serious misconceptions persist around these medical issues and they are limiting the lives of those affected. While culture and attitudes in PNG remain negative towards persons with disability and persons affected by leprosy, how can those affected live the full lives that are intended for them, by the CRPD?

Our recommendations

- 11.i. Persons with disability and persons affected by leprosy should be a regular feature of all Government materials. In doing this, the Government should make a particular effort to ensure that women with disabilities and women affected by leprosy are portrayed routinely. These portrayals may be positive or they may be neutral, but they must never be negative or hurtful.
- 11.ii. We recommend more training for teachers and school students, so that they are able to demonstrate positive attitudes towards persons with disability.

- 11.iii. We recommend that any future review of the school curriculum be done in partnership with Civil Society and Organisations of Persons with Disability to ensure that attitudes of respect and inclusion are inherent within them.
- 11.iv. The Ministry of Tourism, Art, and Culture should appoint somebody within the Ministry who is charged with ensuring greater representation of persons with disability and persons affected by leprosy within media. This Ministry should report back to the UN HRC at the next Universal Periodic Review on the progress that has been made.

12. Conclusion

The purpose of the CRPD is a long way from being achieved within PNG. Although PNG ratified the CRPD eight years ago, many of the issues the Convention aims to address are not being addressed at all.

There are crosscutting issues that are having an impact across the lives of persons living with disabilities and leprosy. Perhaps the most pernicious of these is the one we raised last: awareness. To be a person living with disability or leprosy in PNG too often means the people around you and the organisations you depend on will treat you badly. The lack of awareness around disabilities means that there is, pervasive throughout PNG, a complete lack of respect for people living with disabilities and leprosy. This lack of respect is what has meant that women in hospitals cannot even access a toilet. This lack of respect is what led to a man being kicked off a university course because he uses a wheelchair. This lack of respect is what led to a woman being turned away from a job interview because of her crutches.

Inbuilt within the culture of PNG is a recognition that persons with disability and persons affected by leprosy are to be looked down on and treated differently. Until that is addressed by the Government, the media, and civil society throughout the country, there is little hope that the hundreds of thousands of persons living with disability and leprosy in PNG will be able to access the rights that are their due in a nation that has ratified the CRPD.

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*We have not used the real names of any individuals whose stories we have shared, unless these have already been published in the public domain

¹ University of Melbourne. *'Travelling Together': Disability Inclusive Road Development in Papua New Guinea*. https://msd.unimelb.edu.au/_data/assets/pdf_file/0003/2750691/PNG_ADRA_53770_Literature_review.pdf 2010. (accessed 21 March 2021)

² Human Rights Watch. *World Report 2020*. <https://www.hrw.org/world-report/2020/country-chapters/papua-new-guinea#> 2020. (accessed 21 March 2021)

³ WHO. *World Report on Disability*. <https://www.who.int/publications/i/item/9789241564182> 2011. (accessed 22 March 2021)

⁴ ABC. *Advocates say PNG's disabled community left behind in COVID-19 messaging* <https://www.abc.net.au/radio-australia/programs/pacificbeat/advocates-say-png-disabled-community-left-behind-covid/12533332> August 2020. (accessed 21 March 2021)

⁵ *ibid*

⁶ Humanity and Inclusion. *Accessing Rehabilitation Services: A Challenge To Overcome*. https://blog.hi.org/wp-content/uploads/2019/12/factsheet_iFARstudy_V7-final-WEB.pdf November 2019. (accessed 21 March 2021)

⁷ ABC. *Julie's story gives voice to people living with disability in PNG*. <https://www.abc.net.au/abc-international-development/julies-story-gives-voice-to-people-living-with-disability-in-png/10473616> 18 November 2018 (accessed 21 March 2021)