

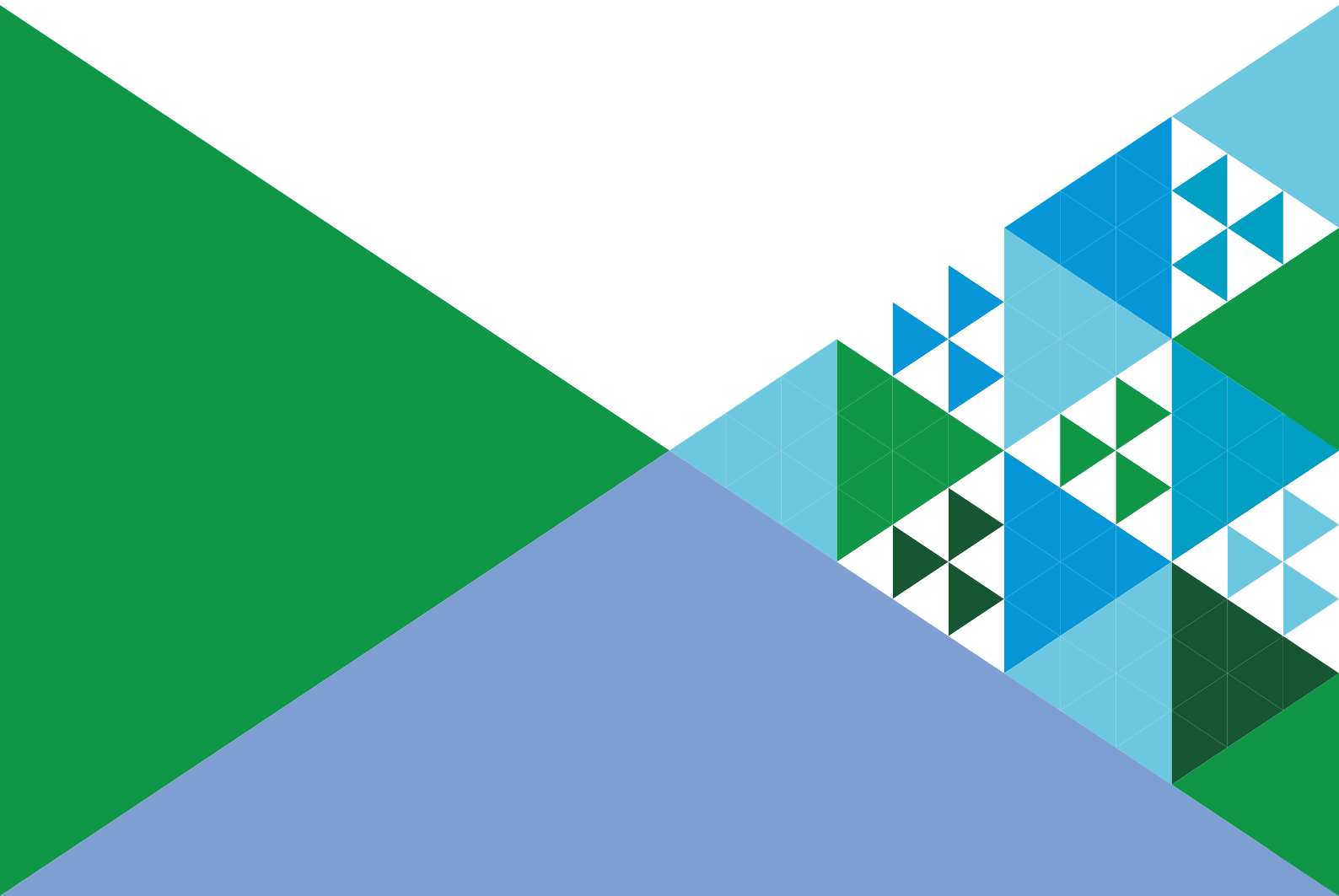


Office of the
Public Advocate

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Experiences of ABI and inclusion

Reflections on inclusion drawn
from lived experience





The Office of the Public Advocate (OPA) acknowledges Victoria's Aboriginal communities and their rich culture. OPA pays respect to their Ancestors, Elders and communities, who are the custodians of the land on which we work.

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Message from the Public Advocate

This report is a reflection piece about experiences of acquired brain injury and inclusion. It brings together themes from a series of interviews undertaken as part of a project that my office began in 2020 called 'Healthy Discussions'.¹

The Office of the Public Advocate (OPA) 'Healthy Discussions' project promotes the right of people with disability to have access to the same standard of healthcare as the general population. It recognises that the foundation for this is the development of a genuinely inclusive society.

The project has included a series of interviews on the theme of human rights that challenge assumptions the general community makes about people with disability.² These interviews have been led by OPA's Healthy Discussions Project Officer, Lisa Brumtis, who brings the lens of her own lived experience of disability to the interviews.

In a number of the interviews, Lisa explores experiences of acquired brain injury (ABI) and inclusion. In this report she brings together themes from her five interviews with people with lived experience of ABI, and reflections from her own lived experience.



Through this report, Lisa invites us to reflect with her on the question of what makes an inclusive society.

Lisa's reflections and the quotes from her interviews provide a powerful insight into experiences of ABI and inclusion. This report demonstrates that listening to the voices of people with lived experience of disability is a vital step towards inclusion.

Colleen Pearce
Public Advocate

¹ The Healthy Discussions project is funded by a grant from the Australian Government Department of Social Services. For more information see: 'Healthy Discussions project', *Office of the Public Advocate (Victoria)* (Web Page) <<https://www.publicadvocate.vic.gov.au/opa-s-work/healthy-discussions-project>>

² 'Human rights interviews', *Office of the Public Advocate (Victoria)* (Web Page) <<https://www.publicadvocate.vic.gov.au/opa-s-work/healthy-discussions-project/human-rights-interviews>>

Message from Lisa

In August 2005, I had an accident which left me with, amongst other things, an acquired brain injury or an ABI. Despite that, I'm still a human being with some of the same fears, thoughts and feelings I had pre-injury.

Acquiring the brain injury was, I believe, one of, if not the greatest thing that could have happened to me. I say this, as it is the event which has brought about so many changes, with so much learning and so many wants and needs and the want to know, the need to prove, I'm not as stupid as believed by some despite my being a person with a brain injury. I know that sounds dreadful, so nonsensical, but that was my world.

This, coupled with my natural desire for knowledge, led me to the need for further study. So I began my journey to find out how I was going to spend the rest of my time.

This began with what I was supposed to do next, beginning with what I was going to do with my knowledge thus far. In my previous life, I had a bachelor of arts. What could I do with that now? The result, which still hasn't come to its end, was further study, beginning with various certificate courses leading to my Graduate Certificate of Applied Human Rights at RMIT University.

The journey is not over yet. I believe I'm on the right track. I do not make any guesses or predictions for the future. I do not trust the future that much. And here I do not want your pity. Simply, some understanding.

Given I'm not supposed to be here, everything that's happening, according to some, is extremely lucky. According to me, very unlucky, but the result of hard work, sometimes really very hard work.

My natural desire for knowledge led me to the series of interviews on the theme of human rights that is part of OPA's 'Healthy Discussions' project, and has led me to reflect on experiences of ABI, inclusion and human rights.

An ABI can manifest in many ways, thus being a very diverse disability, never boring!

I would like to thank and acknowledge Anat Bigos, Manda Laurence, Brent Alford, Peta Ferguson and Neil Cameron. All are strong self advocates who generously shared their experiences and reflections about ABI in their interviews with me. I would also like to thank Associate Professor Dinesh Wadiwel for his interview with me about human rights.

All other reflections in this report are mine alone.

Lisa Brumtis
Healthy Discussions Project Officer

Lisa's reflection on inclusion

What is it?

'Inclusion', what exactly does it mean and how can we make it a reality? Interesting questions, with very interesting answers — yes, more than one — connected to some very challenging ways of thinking. We must then think about 'what type of society' will bring all this into real life.

Very simply, it is the ability to live in a society, which guarantees as far as possible, the freedom to be able to take part in any or all opportunities that may come your way. This may be by using your capabilities, to learn, work, engage and connect with people, services and activities. A very important part of this is affecting, and perhaps changing, decisions that influence society.

This is a very important and basic human right, which is further supported by being, not only a value of the United Nations, but also included in articles of the Convention on the Rights of Persons with Disabilities — in article 19, 'Living independently and being included in the community' and article 24, 'Education'.³

Being included, or belonging, refers to a human emotional need to partner with and be accepted by members of a group. This may include the need to belong to a peer group at school, to be accepted by co-workers, to be part of an athletic team or a religious group. It is about gaining acceptance, attention, and support from members of the group, as well as providing the same attention to other members. The need to be

included in a group can lead to changes in behaviours, beliefs and attitudes, as people want to fit to the norms and standards of the chosen group.

Being human beings, inclusion also means trying to understand differences and intentionally creating policies and practices that deal with that difference. So, inclusion is also about being willing to listen to different opinions and change the way things are done.

Inclusion is the deliberate plan for working with different mindsets, which are then used in trying to work out how society operates and behaves, by setting standards or creating plans, for example the National Standards for Disability Services⁴ or *Practical strategies to promote social integration*.⁵ These can then be used to set priorities and strengthen agreements, so that all are working towards common goals. This agreement about the desired results, can shift society's direction in response to a changing environment.

³ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 19, art 24.

⁴ 'National Standards for Disability Services', *Department of Social Services* (Web Page)

<<https://www.dss.gov.au/our-responsibilities/disability-and-carers/standards-and-quality-assurance/national-standards>>

⁵ 'Practical strategies to promote social integration: Lessons learned from existing policies and practices', *United Nations Education, Scientific and Cultural Organization UNESCO Policy Lab* (Web Page)

<<https://en.unesco.org/inclusivepolicylab/publications/practical-strategies-promote-social-integration>>

Reflections from Lisa's interviews

ABI is quite a complex and unknown area that I believe is worth examining. As part of my series of human rights influenced interviews, I interviewed five people to explore the diverse experiences of ABI.

Quotes from my interviews with Anat Bigos, Manda Laurence, Brent Alford, Peta Ferguson and Neil Cameron appear throughout this report.

Initially, after having the ABI, my taxi driver would always turn to my family, friends or carer and ask them where I'm heading to.

I felt quite inexistence, and as though I don't matter at all. I think this has improved a little.

Anat

I think because my injury is much more invisible than both yours or Peta's, I'm expected to be able to participate in society... People think I'm just the average sort of person, so they can't understand why I have any limitations.

Neil

It was more so... not towards society... I think realising what a brain injury was for me, was more influential.

It's more coming to terms yourself what it is, and for what you can get the strength out of having a brain injury.

And I try and get that strength out of every situation I'm in.

My feeling of what society will look at me was quite brutal for the first five years. But then it was more in terms of when I got full knowledge of what a brain injury was, I turned it into my strength.

So, society's values turned to a positive because I was creating a positive vibe around my injury.

And it took years to where I wanted to be.

Brent

Lisa's reflection on human rights

Human Rights are basic, essential, necessary rights that everyone has, 'without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status'.⁶ They include the right to life; respect for privacy, family, home and correspondence; the right to liberty; the right not to be discriminated against; and so much more.

Everyone has, and is, worthy of these rights — without any discrimination — simply because they are human. It's not enough to have the rights, there needs to be obligations to uphold and enact these rights. These obligations are found in international human rights law, and each member government must act in ways that promote and protect the human rights of the individual.

Since 1948, the United Nations has gradually expanded human rights law to encompass specific standards for women, children, persons with disabilities, minorities and other vulnerable groups. They now possess rights that protect them from discrimination that had long been common in many societies. They now have universal and internationally protected codes to which all nations can subscribe and all people aspire.

The complexities of international law mean that human rights, in that regard,

seem so very far away, so removed from you, the human being.

In theory, the rights of each person cover more areas and the obligations of each government are greater so, you, the entitled person, should be even more protected. The way that this is to be achieved should be quite simple, but realistically, it is not so simple. You must wait, for other people, other agencies, other parties, other jurisdictions, and/or every organ of society, to act appropriately.

If this system is working well, every organ of society plays its part to protect every human being. This is done on an individual level, with individual laws, and on a societal level, with laws targeting groups of society, for example the Age Discrimination Act⁷, the Disability Discrimination Act⁸, the Sex Discrimination Act⁹, the Racial Discrimination Act¹⁰ and others.

If it is working well, after quite a few international twists 'n' turns, every single person has their rights protected on a national and international level — in so doing, protecting every human being on the planet.

⁶ *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/810 (10 December 1948) art 2

⁷ *Age Discrimination Act 2004* (Cth)

⁸ *Disability Discrimination Act 1992* (Cth)

⁹ *Sex Discrimination Act 1984* (Cth)

¹⁰ *Racial Discrimination Act 1975* (Cth)

Interview about human rights

Dinesh Wadiwel is an Associate Professor in Human Rights and Socio Legal Studies from the University of Sydney. I was fortunate to have Dinesh as one of my lecturers.

I recently interviewed Dr Wadiwel as part of my series of interviews for OPA that explore human rights and lived experiences of disability.

Quotes from that interview that resonated with me appear throughout this report.

[T]he simple answer is that human rights are the rights that accrue to individuals because they're humans.

Human rights reflects our status within a community... our ability to be seen and be heard within that community, and that's what human rights expresses...

[Human rights] democratises an elite privilege that was, previously was elite and, available only to a small population, but human rights to me - modern human rights project - seeks to democratise this and make this available to everyone.

So this view would say, actually, the only way that human rights really come into force, mean anything, is that we build a culture where everybody respects human rights...

[W]e all have a responsibility to protect human rights.

Associate Professor Dinesh Wadiwel

Question from Lisa

If human rights are so fundamental and we're supposed to treat each other with respect and dignity, why then the need for them?

[I]n some ways it's a less happy, it's a bittersweet, story about human rights, but it's important to keep in mind that maybe we need human rights now because we've organised the world in a particular way — that they're the last line of defense for some people.

Associate Professor Dinesh Wadiwel



Lisa reflects on ‘What is ABI?’

An acquired brain injury, or ABI, is a term used to describe any type of injury to the brain, that has occurred after birth. This injury may have occurred from: an accident, a stroke, lack of oxygen or degenerative neurological disease.

ABI is predominantly an invisible disability. The consequences are new and different, and as time goes on, they may change in intensity and occurrence. The effects can grow and manifest in different ways.

Given the nature of this disability, the person with the disability is not, in any way, being untruthful. This is as new to the impacted, as it may be to its witnesses.

Added to this, the effects on the individual will differ depending on many features that involve the individual's personality, pre-injury abilities and the severity of the brain injury. This comes from someone who has experienced this, from hearing the experiences of others, and from researching the topic. ABI is severe, sad and the effects seem unbelievable, but given our knowledge of ABI, this is the reality.

I remember thinking, without realising the remarkability of the brain, ‘But I just knocked my head, why on earth are people acting as though I cannot do absolutely anything!’

With time, quite naturally, and with rehabilitation, I got on with life in my very particular way, and probably quite slowly if compared with my previous life.

Along the way, I realised the very many, mixed and quite important, discriminations, coming from the different points of society — simply everywhere. There have been direct, indirect and systemic discriminations, unconscious biases, unthinkable, quite questionable altruism and magnanimity.

While this is happening, you question your existence as a human being, you question your recovery, you question your various relationships, you ask yourself ‘Are you alone?’ That's a hard experience.

You discover you are no longer able to be able to be with other people. Gone are past relationships, new ones are awfully difficult, in that you have to get to know people, as you knew past friends in order to form relationships. That takes time, patience, belief in yourself, belief in humanity.

All this time, you begin to realise that life can't be lived by oneself. So, for a short time, you realise you are alone. Thereafter, while yearning for human contact, you begin to realise that the only people you can have anything to do with are the fellow brain injured. So, quite naturally, you form brain injury friendships. All the while, past friendships are put aside, particularly after periods of isolation.

All this is just my take on ABI. I'm sure that others, have different experiences, learnings and outcomes.

Reflections about ABI from the interviews

When people say, 'Oh, you're an inspiration', I think I'm not interested. I'm just doing the best I can do.

And when I can achieve something I want, I've learnt to congratulate myself.

Manda

With me, I feel that most of society does think this is a simple hurdle one must overcome, and go forward.

And it's taken me so many years, and it's not little at all.

Anat

People don't know anything about it but they judge nevertheless.

Lisa

While I felt that prior to my accident, I could study many languages and many university degrees, post injury I find focusing extremely difficult, and completing sentences really hard.

Anat

Having the ABI for me has shown me what a difficult experience this is.

Prior to the injury, I could go mountain climbing and salsa dancing, where as, now post injury, I can't walk five metres without falling.

I have had therapy constantly, and I think my walking has improved a little bit...

[I]nitially after getting my ABI, I felt I'll be able to do everything again. And only later, I saw it's changed and there's a lot of things I can no longer do, but, it's okay, I've learned to accept.

Anat

Yes, you find out after a little while, once you realise what you're not able to do anymore. You don't know immediately, but you get to learn after a while.

It takes a long time to get used to the things that you can't do anymore...

Some things get better, some things get worse.

Manda



How long have you had your acquired brain injury?

41 years.

Neil

I had mine since 1983.

Peta

After my brain injury, I was just like a new person. I mean, different in the same body, but a new person. So, my whole life was changed accordingly...

[M]y memory has changed substantially following my accident even. My memory and remembering how to do things that I did previously was very difficult, and so I had to have a big re-learning and you can't re-learn. It's very slow. And even today my memory, my short term memory, is not very good at all.

I don't know how to describe it really. I just really, unless I write things down I really don't remember what I'm supposed to be doing, and I don't remember really what we're doing yesterday or two days ago. I have to have it written down to check.

Neil

So your short term memory is bad?

Yeah, and it has been all this time.

Neil

It affects different people differently. My short term memory is okay. But now is deteriorating a bit. I put that down to encroaching senility. [Gentle laugh]

Peta

After recovering and rehabilitating, did you find that your thinking had changed?

It has to, because if you are too busy worrying about what you used to be able to do, you just get too distressed.

And to some extent, I learnt that I can do many of the things I used to do, I just can't do them as well.

Manda

[I]t has enabled me to be put into a community, I suppose, with like-minded people who are trying to get the better of themselves having a brain injury.

I think if you keep learning every day, becoming that better person, or where you want to get to, I think that's how it's changed me.

Brent

[I]t's given us the opportunity to increase our appreciation of the little things that before we took for granted...

Anat

It's a mindset.

So if you're really positive about everything, you turn all the traits into positive things, but if you're negative, you turn them into negative.

So it depends on how you are that day, or that week, or that time of month, or whatever. It depends how you're feeling about your brain injury.

I'd say get yourself involved in a community... When I say community, a group of people who have brain injury that all understand what you're going through.

It's all about how you're feeling. There's still going to be bad days, and just work through it and know that tomorrow's going to be better.

Brent

Do you find yourself trying to convince other people of your traits? Old friends, perhaps new friends?

I don't have any old friends.

Yes. Initially, people were very helpful and stood by you and you know, did things. But as soon as you're supposed to be well, which is probably about after a month, they decide they weren't really able to help you anymore. And so you had to do everything yourself.

Neil

Did you say after a month?

Well, a couple of months. I was in rehab for over six months. So while I was in rehab, they probably... I even had visitors even there... But after I left rehab, people came and say, you know, 'That was unfortunate. You certainly had a bad accident, but you're right now, aren't you?' You know, everything's fine. And so they expected you to be okay and when you weren't it was just unfortunate.

Neil

Either people embrace you or people run away from you.

Peta

Lisa's reflection on human rights and inclusion

Human rights

Human rights are, by their nature, inclusive. They clearly, and quite beautifully, express the very broad rights and freedoms that we are all granted and entitled to. The Universal Declaration of Human Rights is available in over 500 languages.¹¹ The international community has to support and protect human rights. It needs to guarantee, as much as it can, that these rights exist for all humanity: every man, woman and child, everywhere.

The Universal Declaration begins by stating, 'All human beings are born free and equal in dignity and rights.'¹² This is followed up by obligations on all States to bring into reality all the economic, social, political, cultural and civic rights,¹³ to form a base for a life which is free from want and fear. Human rights are not country-specific, nor are they specific to any group or time. They are basic freedoms for all people, at all times, and in all places.

To be realistic, human rights abuses did not come to an end with the adoption of the Universal Declaration, but since then, a great number of people have gained greater freedoms, as well as some abuses being cut back, or even stopped.

Added to this, a great number of people have gained justice for wrongs, protection on national and international

levels for their rights. This has happened because of the strong international human rights laws.

To add to this, there are a number of domestic laws, that may not be labelled as human rights laws, but protect a person's rights, for example civil, constitutional, social and citizen rights.

Despite there being protections — legal, moral, social, theoretical, rights — there are a number of humans who experience abuses and wrongs. Clearly this is simply not enough. Abuses continue to happen, but in a different more clever or cunning way. I don't believe I have anything more to say about this fact - this is life!

Human Rights also have the power to inspire us all, by creating ideas to change the world in order to work for all people to gain freedom, equality and dignity. And importantly, to allow all people to demand what should be guaranteed: their human rights.

What this means realistically is this: human rights are a way for us all to come together and show elements of our humanity. This is regardless of the various features of a person: personality, individuality, society, culture, humanity.

Human rights are about our need to engage in services or activities and are about being able to take advantage of life opportunities. They benefit our health

¹¹ 'Universal Declaration of Human Rights, *United Nations* (Web Page)

<<https://www.un.org/en/about-us/universal-declaration-of-human-rights>>

¹² *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/810 (10 December 1948) art 1

¹³ *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976)

and promote our togetherness, providing a better path to being quintessentially human.

Inclusion

A focus of inclusion is to break up any barriers and replace them with settings based on the individual's needs, in a way that changes the settings to fit the needs of the individual. This to allow all individuals, regardless of their abilities, to fully participate in their political, economic and social life, thus improving opportunity and the dignity of all participants.

Inclusion makes economic sense because it increases opportunities to gain employment and addresses poor education, which goes on to effect employment outcomes. As well, there are costs of exclusion which can include racism, discrimination, social tensions, and risks of violence and conflict.

Can inclusion become a reality?

In order for inclusion to become a reality, there needs to be obligations on organisations which have to be acted upon.

This is important so as to, perhaps, create a Utopia, an ideal society¹⁴, one in which everyone can experience inclusion. This is a society where all people with a disability, all women, all children, and all groups generally are treated with respect and dignity. This is a society where the individual members of society are also respected. This is a society in which the economic system allows all members to follow their work and the life they wish to pursue.

An example of attempts to create inclusion, are various World Bank projects which emphasise social inclusion, particularly after the COVID-19 pandemic. The pandemic is looked at as an opportunity to rebuild inclusive systems, against possible future shocks: health, climate and natural disasters, as well as social unrest. All this, in order to improve the lives of various groups, communities or societies, so as to have an equal opportunity to experience social inclusion and have the appropriate resources to prosper.¹⁵

Theoretically, inclusion can become a reality, but personal experience tells me that theories are just that, and in no way realities. However if, as humanity, we decide that inclusion is the way we want to go, human rights is the only choice we have to get there.

¹⁴ 'How Utopia shaped the world', BBC Culture (Web Page)
<<https://www.bbc.com/culture/article/20160920-how-utopia-shaped-the-world>>

¹⁵ 'Social inclusion', *The World Bank* (Web Page)
<<https://www.worldbank.org/en/topic/social-inclusion>>, 'Thriving in a Modern World: The Importance of Diversity and Inclusion', *EKU (Eastern Kentucky University) Online* (Web Page)
<<https://ekuonline.eku.edu/blog/social-work/thriving-in-a-modern-world-the-importance-of-diversity-and-inclusion/>>, 'Leave No One Behind', *United Nations Sustainable Development Group* (Web Page)
<<https://unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind>>

Inclusion, human rights and dignity

Because of my limitation I don't feel included in society. But that's not society's fault. That's my limitation, e.g. I can't work and I stay out of certain things I just can't do.

So I am limited for my full involvement in society, just through my limitation.

Peta

I don't know if I necessarily agree, but thank you.

Lisa

What I would say is that we all participate in social and political communities, and in order to participate, we all have to be granted equality and respect.

[I]f we want a community that is premised upon democracy, upon respect for individuals on an equal basis, then we would want a community that respects rights of individuals.

Associate Professor Dinesh Wadiwel

Dignity is one of the hardest concepts to unpack. It's actually quite essential to the human rights project...

[O]ne way to view the Disability Rights Convention is that it seeks to both say to the international community, 'Hey, this group of people who you presumed have no dignity, actually do have intrinsic dignity'. And simultaneously it sets the program and says, if we're going to recognise this dignity, this is what we need to do to change society, to fundamentally recognise it and support people with disability to have their dignity recognised by others...

[T]he Convention on the Rights of Persons with Disabilities... I would say, and I teach my students, in some ways it is the most, one of the most advanced treaties in bringing together civil and political rights and economic, social and cultural rights.

So to give you one example, one of the, I would say, one of the most amazing articles in that treaty is Article 19 on the right to live independently in the community. And that article is, partly refers to, a classic right, which is freedom from arbitrary detention. And as you know, many people with disability don't

get to choose the circumstances that they live within. And some people with disability have been subject to forced institutionalization through their whole life. Just because they are people with disability.

[The Convention on the Rights of Persons with Disabilities] proclaims into law, both international law and hopefully into domestic law, how individuals should be treated and raises this to the level of law in that it's meant to bind nation states and bind institutions, and can actually lead to forms of law that are enforceable.

Associate Professor Dinesh Wadiwel



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