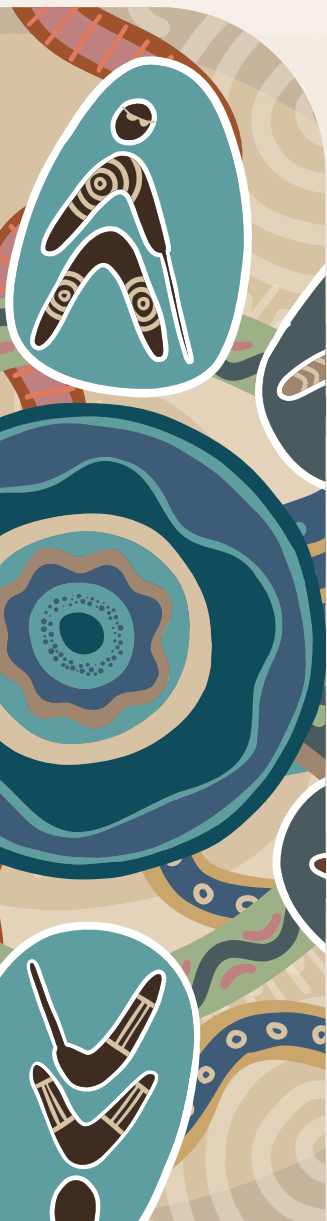
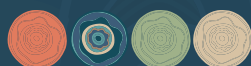


International Day of People with Disability Yarning Guide

A guide to help start conversations in the community about disability.





The Australian Government acknowledges Aboriginal and Torres Strait Islander peoples throughout Australia and their continuing connection to land, water, culture and community.

We pay our respects to the Elders both past and present.

We thank the Aboriginal and Torres Strait Island people who live with disability and generously shared their personal stories for this yarning guide.

We also acknowledge the Aboriginal and Torres Strait Islander people in the images throughout this guide. These photos celebrate their culture and offer a look into their daily lives.

Please note that the people in these images are not the people who shared their stories for this guide.



Contents

Seen and Unseen	4
About Aneika Kapeen	5
About this Guide	6
What is IDPwD?	7
What is disability?	8
Darlene's Story	9
The social model versus medical model of disability	11
Emily's Story	12
Start the Yarn	14
Wayne's Story	16
Bonnie's Story	18
Language Matters	20
Maddie's Story	21
Next steps	23

Seen and Unseen

Seen and Unseen is an artwork by Aneika Kapeen, bringing together different journeys and experiences of disability, recognising that disability can be visible or unseen.

At the centre of the design, community gathers around those who may need support. The surrounding figures and pathways represent care, inclusion and the many different ways people move through life. Each person carries their own story, identity and experience, while remaining connected through shared understanding and collective responsibility.

Patterned sun forms sit throughout the background, symbolising visibility, awareness and the importance of bringing disability experiences into the light. The layered pathways reflect movement, change and the individual journeys people take when accessing support, connection and opportunity.

Blues, greens and earthy tones create a grounded connection to Country, community and wellbeing. Brighter coral details introduce warmth and energy, representing hope, strength and moments of positive change.

Together, the artwork tells a story of inclusion, recognition and communities walking alongside people with disability.



About Aneika Kapeen

Aneika Kapeen is a Yaegl and Bundjalung woman. She is known for her extensive contributions to her community, particularly in the realm of education and cultural preservation.

Aneika is the founder and CEO of the Mudyala Aboriginal Corporation. She has dedicated her life to supporting Aboriginal and Torres Strait Islander youth in the Northern NSW Clarence Valley region.

Born and raised in the Clarence Valley, Aneika's journey into community leadership began at a young age. She was motivated by her experiences as a mother struggling to access early childhood education for her children. This led her to establish the Mudyala Aboriginal Corporation, which now runs various programs to support youth and their families.





About this Guide

There are 5.5 million people with disability in Australia. That's 1 in 5 people.

In Aboriginal and Torres Strait Islander communities, 37% (about 367,700) reported living with disability in 2022-23 (Australian Bureau of Statistics).

This Yarning Guide aims to help start conversations in the community about disability.

The purpose is to:

- challenge stereotypes and negative attitudes
- recognise the diversity and experiences of First Nations people with disability
- share stories and information in a culturally safe way
- build a more inclusive and supportive community.

This guide focuses on real people and their individual stories. Everyone's health, disability, support and care needs are different.

By sharing their experiences and using yarning questions, this guide aims to help communities talk openly about disability.

When we have open discussions, we can build understanding and create more inclusive communities. It can also shape how we support people with disability at an individual and community level.

This guide was developed by IM Agency, a First Nations-owned business, along with First Nations community members, to support culturally informed conversations about disability.

What is IDPwD?

International Day of People with Disability (IDPwD) is on 3 December each year.

This United Nations day aims to promote awareness, understanding and acceptance of people with disability.

In Australia, IDPwD is a joint effort between governments, schools, organisations, community groups and individuals.

It's an opportunity to recognise the different journeys and contributions of people with disability. There are many ways to do this on 3 December and all year round.

For more information and resources about IDPwD, please visit www.idpwd.gov.au.



What is disability?

Disability can be physical, cognitive, intellectual, neurological or sensory. It can be visible or hidden. People can face barriers because of the way society views and responds to disability.

Disability can last your whole life or a short while. People may need different kinds of support at different times and disability may change over time.

Living with disability is a journey that everyone experiences differently.



Yarning prompts

How can our definition of disability influence the way people with disability feel included, respected and valued?

Disability is a unique journey for everyone. How can we grow our understanding of different experiences of disability?

Darlene's Story



Independence. Dignity. Resilience. Family.

I'm a Bundjalung woman from Tabulum, living in Northern New South Wales. I'm the fourth of 9 children. For about 40 years now, I've been living off the mission, making my own way.

Life threw me a curveball when I was diagnosed with diabetes at 18. For a long time, I'll admit, I was stubborn. My family warned me, and the doctors gave me advice, but I didn't always listen. By the time I hit 50, complications started setting in and 4 years ago, I lost my leg. It was a hard lesson in what happens when you don't take those warnings to heart.

I never let myself sink into depression. But there was one moment that really hit home. It was the day I realised I couldn't just pick up my young grandson like I used to. That was tough, but it didn't break me. It just made me more determined to stay as independent as I could.

I've always been determined. I do my own cleaning and washing and I make my own bed every single day. I do it for myself, but also to prove to everyone else exactly what I'm still capable of.

Dignity is everything to me. I prefer my walking stick or my prosthetic leg. I usually wear long pants to keep my amputation private. It's my business. I've even had to set boundaries with my care workers. I'll tell them straight: 'I can put on my own shoe.' I only ask for help when I truly need it.

My grandkids call me 'Wonder Woman.' They watch me move from my wheelchair to my bed all by myself, and they're amazed. I use those moments to teach them. I tell them, 'Look at what too much sugar and lollies can do.' I hope they'll learn from my journey and take better care of their health than I did.

Family is my heartbeat. My grandsons are turning 8 and 10 now, and there's nothing I love more than spending time with them. Their support keeps me going.

My message to my community is this: don't let mental blocks or a bad attitude limit you. If you have the will, you'll find the way.

I think it's important to raise awareness of disability and to make sure we aren't just seen as people with disability. We're people living our lives, full and proud.



Yarning prompts

How does community shape how people see their disability and challenges?

How can family, community and culture support people with disability?

What can we learn from our Elders about resilience, independence and strength in hard times?

The social model versus medical model of disability

The medical model sees disability as something that needs to be fixed or cured.

The social model says people with disability can face barriers in their community. These barriers can be physical, social or people's attitudes toward disability.

The social model aims to make the world more inclusive by removing barriers for people with disability. For example:

- Systems and policies that limit opportunities for people with disability.
- Negative attitudes, like thinking someone can't do a job because of disability.
- Not knowing about or understanding disability.
- Physical barriers, like buildings without ramps or lifts.



Yarning prompts

How can our attitudes affect the experiences of people with disability?

What can we do to make community more inclusive and accessible?



Emily's Story

Adjustment. Self-Advocacy. Stereotypes. Awareness.

For some, disability arrives suddenly and adjusting to a new way of life takes time, patience and resilience.

I am a proud Waarri Yamatji woman. I ran a successful business before my life took an unexpected turn. It started with a mild stroke, which eventually led to being diagnosed with rheumatic heart disease and chronic fatigue syndrome.

Moving from a life of total independence to navigating chronic illness was a massive shift. Not just physically, but emotionally and mentally, as I learned to embrace this new version of myself.

When the world felt a bit lonely, I found my greatest strength in the love of my family and my loyal dog, who actually saved my life.

Through it all, I became a fierce believer in speaking up for myself. When doctors initially brushed off my concerns, I didn't give up until I found a doctor who truly listened.

I encourage others walking a similar path to trust their instincts. Seek a second opinion if something feels off. Remember that finding a supportive medical team is one of the most important steps you can take.

International Day of People with Disability is a good way to raise awareness. But real change happens when people truly understand each other.

Disability doesn't have just one look. It is as varied as the people living with it. I hope people can get better at looking past the surface. I hope they stop making assumptions about someone's health based on what they see on the outside.



Yarning prompts

What can community do to support people with disability through their journey as it changes?

How can health professionals really listen and respond to the needs of people with disability?

How can we challenge the idea that disability has to look a certain way?

Start the Yarn

It's okay if you feel unsure about what to say. Don't worry about being perfect. Just be respectful, open to learning and listen.

It's important to include people with disability when you talk about disability. You can do this by:

- Inviting people with disability to lead activities or speak.
- Paying people with disability for their time, skills and knowledge.
- Making sure spaces are safe, comfortable and easy to get into for people with disability.
- Understanding that people can contribute in different ways.



Yarning prompt

Why is it important to have more people yarning about disability?



Make sure your events, catch-ups and yarnning circles are easy for everyone to join and are culturally safe.

Think about these things:

- Physical access, like ramps and bathrooms.
- Support for different communication needs.
- Giving simple and clear information.
- Providing documents that work with screen readers.
- Making sure carers are also welcome.
- Quiet and calm spaces.
- Giving everyone enough time to take part.

Yarning prompt

How can community create safe and welcoming spaces for people with disability?



Wayne's Story

Country. Pride. Yarning. Responsibility. Healing.

I live in Geraldton, Western Australia as a Nyoongar person. Life has taught me that strength is found in family, connection to Country, and the quiet, steady work of supporting those we love. Reflecting on my own start to life on a reserve in the 1950s, I see how far we've come. But I also see the new challenges my grandchildren face. My life today is focused on them.

I am part of a close-knit family who care for 4 grandchildren. Two of my grandsons are neurodivergent. They have distinct needs that require extra attention, care and a stable, predictable environment. My role is to be part of a support system for my daughter. I step in to provide help where required so she can work and ensure the boys have the consistency they need.

Raising children with disability can be busy, demanding work. There are meltdowns and hard days. But these are just part of the reality of our 2 households, and we manage them with patience. We all rejoice in the fact we are seeing progress. Recently, after a change in medication, the 14-year-old has made great strides at school.

For us, the path forward is tied to our culture. I share stories and photos of our parents and grandparents to instill a sense of pride, responsibility and hard work. We teach them about their family tree and heritage to build a strong sense of identity.

I believe these cultural connections will help them navigate a world that isn't built for neurodivergent individuals. We are always looking for an opportunity to take the grandchildren on 'Boodja' (our Country). We walk barefoot to feel the earth, recharge our cultural batteries and find true healing.

While there is still stigma around disability, we manage it by focusing on what matters. Our family, our neighbours who support us and our connection to each other.

I'm still learning every day. I prefer yarning over reading reports to learn about neurodivergence. I'm always looking for better ways to advocate for my grandsons.

I believe International Day of People with Disability is a great way to help normalise these conversations. It reminds us that we aren't alone.

By sharing our story, I hope we can help build awareness, acceptance, and a stronger, more supported community for all our kids.



Yarning prompts

What role do Elders play in supporting the next generation of people with disability?

How does culture and Country support the health and wellbeing of our communities?

How can organisations better support people with disability in our community, including schools, NDIS and the health system?



Bonnie's Story

Neurodiversity. Stigma. Advocacy. Indigenous-led healthcare.

I am a proud Kamilaroi woman, living in Garramilla (Darwin) on Larrakia Land for over 10 years now. I was only recently diagnosed with epilepsy, autism and ADHD.

Having both autism and ADHD is sometimes called AuDHD. The 2 conditions can interact, so experiencing both can feel different from having either one on its own. Because all of these diagnoses are still new to me, I'm still getting used to thinking of myself as disabled.

Most days, I feel 'normal' and don't think about the challenges that come with my disability. And because you can't see my disability, I feel undeserving of that title at times.

Despite this, it feels really validating to get diagnosed with autism and ADHD. I've learned so much about myself. I see the way I think, act and feel as more of a superpower than a quirk or challenge. This has allowed me to learn a lot and to feel more comfortable in my own skin.

I will admit it has been a massive challenge to navigate the health system to get my diagnoses and right treatment. When I first got my referral to the neurologist, I was told there was only one in Northern Territory. It took until I nearly died having a seizure to see him. I also waited nearly 2 years to see a psychiatrist to get diagnosed with autism and ADHD, and I had to pay for a lot of it myself.

During both processes, I have needed to prepare to speak with doctors. I feel like they continue to dismiss my concerns when I raise them. It takes a tiring amount of self-advocacy just to get basic care.

I often worry about others in our community. If it's this hard for me, with my education and research skills, how are mob supposed to get help? We shouldn't need a degree, or a folder full of research, to be heard and believed by a doctor.

On the upside of all of this, I realised that I'm not alone. I learned how vital it is to have friends and safe spaces where we can share these things and feel understood.



Bonnie's Story continued

I've found community in a group chat that my tidda created that's full of other 'neurospicy' blackfullas. Some of us are diagnosed, some of us don't need a doctor to tell us – we just know. It's a great space to share the good days and the bad days. Sometimes we share memes and videos that we know people will just get.

I think neurodivergence is wildly unrecognised and undiagnosed in Blak communities. Part of that is us having a stigma around mental health. But it's not a bad thing. Being honest about who you are, and knowing how you are, is empowering.

My vision for the future is where all mob get the support we need. Whether we have disability ourselves or have family and friends with disability.

We need more than just clinics. We need support that meets people where they are, in familiar and low-pressure spaces. We need opportunities to connect online and in person, like a barbeque at the Aboriginal Medical Service. Who doesn't love a sausage sanga?! Also practical help, like assistance to access specialised services and transport. And support people who can help us navigate what can be scary and complex processes.

Real change will take generations. It's up to us to help our communities and our young ones to feel better supported in health care and disability spaces.

Yarning prompts

How can we help build understanding and acceptance of disability in our communities?

What would make it easier for people in rural and remote areas to access support and services?

What helps people with disability to feel culturally safe and respected when using services?

Language Matters

The way we talk about disability is important. The words we use can affect how we see and treat people with disability.

Some simple things to remember:

- Focus on the person, not the disability.
- Using respectful language helps everyone feel included.
- Avoid using negative words like victim, sufferer or handicapped.
- Talk directly to the person, not their interpreter or support person.
- Avoid using words like brave or inspiring as this can make people feel uncomfortable.

It is usually best to use language that puts the person first by saying 'person with disability.' However, some people prefer to identify their disability first with terms like 'Autistic person.' And others may not want to use a label at all.

If you are unsure, just ask people what they prefer.

Yarning prompts

How can words and labels have a positive or negative impact?

How can we change the way we talk to focus on people's strengths, rather than just the challenges?



Maddie's Story

Hidden Disability. Culturally Safe Care. Strength from Ancestors.

I am a Gomeroi woman from northwest New South Wales. My journey with disability began long before I even knew I was sick.

I was born with a heart condition that went undetected for nearly 2 decades. It wasn't until I was 18, hospitalised, and struggling, that a nurse noticed the clubbing in my fingers and my low oxygen levels. That led to my diagnosis of Eisenmenger Syndrome that changed the course of my life forever.

Without intervention, Eisenmenger Syndrome is terminal. The reality of a limited life expectancy is a heavy burden to carry. I've been placed on a transplant waiting list. This brings a unique set of emotional challenges, as you wait for a call that will give you a second chance at life.

Navigating the healthcare system has shown me the importance of culturally safe care. While I have faced barriers in the past, it has been vital for my wellbeing to have a medical team that listens and respects my needs as an Aboriginal woman.

It has been difficult navigating what I prefer to call 'hidden disability'. Eisenmenger Syndrome isn't visually obvious, so people often overestimate my physical ability.

I have learned to be blunt and assertive, such as dealing with taxi drivers who don't understand why I need assistance. I believe it's crucial to move away from the term 'invisible disability.' My daily reality is not invisible to me. I need to constantly adapt and advocate for myself.

During this journey, my connection to Country and my Ancestors has been my greatest source of strength. Spirituality provides me with comfort. It helps manage the isolation that often comes with rare disease treatment.

My cultural identity is inseparable from my healthcare. For instance, I have expressed a deep wish to keep my organs after my transplant. This is so I can conduct a ceremony on Country. It's important that we return them to the land that has sustained my mob for tens of thousands of years.



Maddie's Story continued

My experiences have made me a passionate advocate. I want to bridge the gap in cultural understanding in medical settings. Especially with organ donation among First Nations communities. I know effective advocacy is built on listening, learning and educating others.

By sharing my story, I hope to create a world where accessibility is a standard, not an afterthought. A world where cultural values are respected as a fundamental part of the healing process.

Yarning prompts

How can we create spaces where people don't feel pressured to explain or justify their needs?

How can people stay connected to their culture, spirit, family and history when getting or giving support?

What can services do to better respect and support cultural practices?

Next steps

Learning to be more inclusive is a journey, and this Yarning Guide is just the beginning.

Once we start to have conversations about disability, people may feel more confident talking about disability in an inclusive and respectful way.

For more information, you can visit www.idpwd.gov.au to:

- learn more about how to get involved in IDPwD
- watch and read stories about people with disability.



