# with us



ISSUE 2 • NOVEMBER 2021

# Big thanks...

Cover artwork by the wonderful **Nina Sepahpour**, a textile designer and freelance artist who works on projects across illustration, print and graphic design.

Exploring layers of motif, pattern, shape and colour, Nina is passionate about creating engaging and playful designs that bring stories to life.

She is driven by innovation, excited by nontraditional methods of work, community projects and collaboration.





minasepahpour.com O Oninasepahpour



High fives and huge thanks to all of the awesome contributors to Issue 2 of with us.





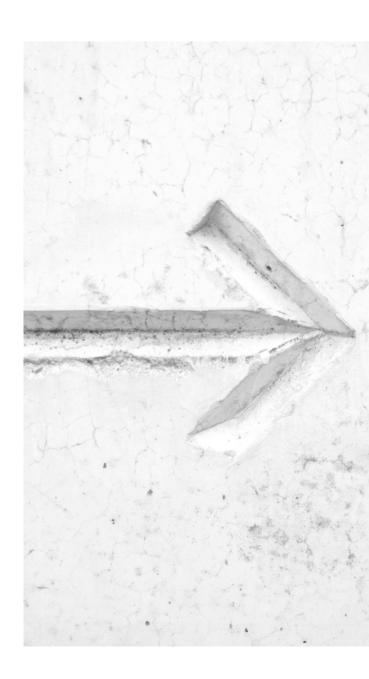


We acknowledge the Aboriginal and Torres Strait Islander peoples as the first inhabitants of this nation and the traditional custodians of the lands where we live, learn and work. We value their cultures, identities, and continuing connection to country, waters, kin and community. We pay our respects to Elders past, present and emerging.

We acknowledge and pay our respects to the voice of lived experience, their families and support people; to those who use their personal experiences of ill health or circumstance in the hope of shaping a better future for themselves and others. We thank them for finding the extraordinary strength and determination it takes to revisit often painful memories in order to make a difference.

## In this issue...

- Welcome to with us nothing about us without us issue
- The Future is Bright
  A collection of conversations from 7
  exceptional advocates and leaders
- 10 Christina Ryan
  Learning from our history to shape the future of disability advocacy and leadership
- 16 Tim Heffernan
  Standing on the shoulders of giants the development and growth of lived
  experience workers
- 22 Ingrid Ozols AM
  Listening and learning from lived
  experience is the foundation of a better
  future
- **22** Arshdeep Cheema
  Trailblazing change for migrant and refugee inclusion





- **36** Eva Sifis

  People with lived experience have a PhD in getting better using my brain injury recovery to inform change in
- 40 KC
  Put your ego aside, there is always more to learn
- The 2021 working with survey

  Tell us what being part of lived experience engagement is really like
- 48 Sonia Sanchez Moreno
  Language Matters
- The With Us Thumbs Up

  Tools, resources and contemporary
  pracitce that get the With Us thumbs up.
- 54 Stay in touch
  Register and subscribe

## **Editorial**

Welcome to the *nothing about us without us* issue of With Us.

This issue is a virtual high five for lived experience advocates, leaders and champions – those who draw upon their firsthand experiences to inform change. It's about celebrating their strength, tenacity (and all-round awesomeness) + shining a light on the many ways they transform the words 'nothing about us without us' into real life action that changes lives.



As someone whose personal + professional experiences led to the work I now do - embedding lived experience led approaches into the design, development and delivery of products, services and systems for community – I know only too well the blood, sweat and tears that go into encouraging, educating and supporting organisations to mature their engagement approaches away from buzzwords and tokenism, towards meaningful results where everyone benefits.

Even though **working with** people with lived experience is a requirement for the design and development of many health and community products, services and systems, the way that people + communities are included and involved is still pretty hit and miss.

Despite these frustrations, shining through the cracks I see rays of hope in the form of pockets of growing understanding and appreciation of...

- the value of *working* [in partnership] *with* people with lived experience
- the need to get it right, and
- more and more organisations that are willing to learn and do better.

## When I look to the potential and future [of working with], I imagine more voices and more tables worth sitting at.

**I imagine a choir of change makers,** advocates, leaders and champions from many walks of life. A choir of united voices **singing together for change.** 

The thought of this choir keeps me smiling and trying on the days when it feels like an uphill battle.

In this issue, you will meet a mighty fine selection of lived experience advocates + leaders who have so kindly shared their real stories of 'nothing about us without us'. A mini choir made up of gutsy lived experience pioneers who have paved the way, and those who are newer on the scene with so much to contribute. All full of passion, energy and ready to help carry the torch of change, to keep it burning as we move together into the future.

If you believe in the power of **working with**, I hope that issue #2 leaves you reassured and hopeful that there are other excellent humans out there on the same path. That there is hope for this way of working to be the catalyst for change.

I hope that you recognise the sweet smell of possibility in the stories and insights shared and that you use them to inspire and inform your own **working with** adventures.

Sue

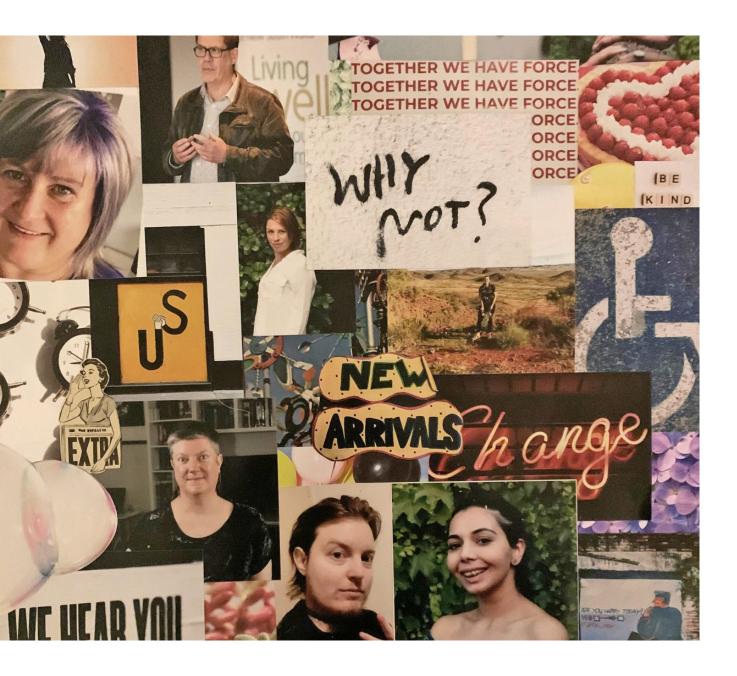
This issue is dedicated to Jackie Crowe. An exceptional human + irreplaceable trailblazer who may be gone but whose voice + place in the choir will always remain. The sound of her wicked laugh + inquiring words "and what are you going to do about that?" echoes on in the ears of so many of us who were blessed to know and work alongside her.

"Things will change, but only if our voices are amplified. We will do it together – many voices, one purpose – better outcomes for people, families and communities."

- Jackie Crowe (1968 - 2017)

# The Future Looks Bright

How can you not be hopeful for the future of *working with* when there are exceptional advocates and leaders like Christina, Tim, Ingrid, Arshdeep, Tiarnee, Eva and KC out there in the world making noise, taking action and paving the way for change.



# Learning from our history to shape the future of disability advocacy and leadership

**Meet Christina Ryan** 

Meet the awesome Christina Ryan who has been an active leader in the disability community for over 20 years, working at an international, national and local level to change the diversity agenda.

Aptly described as the 'gardener of leaders', Christina Ryan is also the CEO and Founder of the Disability Leadership Institute, an organisation whose foundation is built on her passion and dedication to promoting, developing and supporting leaders with disabilities. The Disability Leadership Institute aims to grow the presence and recognition of disability leaders across all sections of the community.



We spoke to Christina about her adventures in disability advocacy, all that she has learned along the way, and her vision for the future of 'nothing about us without us'.

#### Tell us a little bit about Christina + how you came to be doing this important work. What is your why? What sits at the heart of all that you do and is the reason that you keep on going?

I spent about 20 years working in the community sector, including time at the frontline of disability advocacy as well as a volunteer working on the intersection of gender and disability.

What became clear is that violence is the single biggest issue facing disabled people, particularly disabled women, and that nothing was changing despite the effort that so many people were putting in.

One day at a team meeting I realised that the problem was structural inequality. We couldn't address the levels of violence until we addressed the fundamental structural inequality experienced by disabled people. We are simply not equal.

At the same time, I looked around and realised that in my decades of working as a disability activist there had never been an ongoing commitment to disability leadership. We'd had a handful of pilot projects, or small one off courses, but there was no consistent attention being given to developing and supporting disability leaders.

I decided to use my expertise and experience to address the structural inequality by growing a space for the development of disability leadership, and the support of disability leaders.

The immediate response from the disability community told me that this was long overdue, and 5 years later we are still here and growing.

#### The growing opportunities for people with a disability to work with services, organisations, and governments, didn't just magically happen. Could you tell us a bit about the disability advocacy movement?

The term disability advocacy means different things to different people. For some, it's what disabled people do when we get out and change the world by asserting our rights. For others, it means anyone who works in advocating for disabled people, or disability issues.

I always interpret it as meaning disabled people speaking up about our rights and the change that we want to see in a world that doesn't listen to us very often.

Many services, and most governments, still have very few disabled people in leadership and decision-making roles. The disability community, by that I mean disabled people, is pushing hard to change this, but it's a tough gig and we've barely made any inroads yet.

A lot of people talk about the importance of hearing from disabled people, but they don't quite consider that to mean giving up their own positions of power to do so.

#### What does 'nothing about us without us' mean to you and to the disability advocacy community?

I can't speak for my community; I no longer have representative status. For me it means 15 per cent of global leaders (that's how many disabled people are on the planet) are disabled people. If you look around you, you'll get that we have a long way to go.

Organisations that have a focus on disability, government agencies and service designers and providers should have at least half of their workforce and leadership teams being disabled people, including boards.

One day we might have all disability ministers being disabled people as well, that would be excellent! A bit like all the ministers for women are now women.

### What did disability advocacy look like when you first started out, and what changes have you seen over time?

There hasn't been huge change, most of it is very subtle. I'll never forget the first time I saw the term 'disability leadership' go past in my LinkedIn feed from someone I didn't know. That's when I realised things were changing and that the constant talk was making an impact.

Possibly the biggest change is that there is now an expectation that disabled people should be in the room when we are being discussed. It doesn't always happen, particularly in government, but in the community sector it's not possible to be credible anymore unless disabled people are driving what is happening.



#### Aside from yourself, who are the disability leaders to which we owe a debt of gratitude?

Goodness, there are thousands of us out there. Our early pioneers who established the Disabled Peoples Organisations, often in the face of fierce opposition, those who wrote the Convention on the Rights of Persons with Disabilities, others who chained themselves to trams to force accessible public transport...these are the people I look to and am inspired by.

I love the highly intersectional nature of the disability community. We have wonderful folk working across a range of spaces, like disabled First Peoples, people in the multicultural communities, heaps of LGBTIQ folk.

Something I particularly love about being part of a movement is that its huge and diverse. We tackle change from all angles.

#### What are you most proud of in your work in this field?

Apart from my current work, I remain proud about getting intersectional language into mainstream UN documents for the first time about a decade ago. It was a tough fight, but we got there.

I am also incredibly proud of the wonderful people I've met who have since gone on to do massive things. Former colleagues, team members, collaborators. If I've contributed even slightly to what they are doing, then I'm stoked.

#### Where would you do things differently if you had your time again?

I don't believe in "what if" or regrets. I am so privileged to have lived the life that I do and to have made a difference to the world around me.

#### Is there anything that you feel has held the disability advocacy community back?

The attitudes of others. We are often assumed to be working at entry level or to not be objective about what we are seeking, yet we have people of great wisdom, expertise and passion who are truly outstanding and should be in the room. We are held back by centuries old prejudice.

#### What has been its greatest strength?

Our diversity. Having such an array of intersectional, highly talented folk, all working towards the rights of disabled people from their various angles means we are chipping away at the monolith of oppression.

#### How do you mentor and support new people starting out in this space?

My first thing is to get people to stop saying sorry. To stop apologising for existing. Be yourself and know that it's wonderful, valuable and worthwhile.

Everyone is equal, and we learn from each other all the time.

#### If you could give developing + emerging leaders one piece of advice, what would it be?

Own it. Your disability gives you entry into this wonderful, challenging and vibrant community. Be proud of who we are as disabled people.

#### What are the opportunities for the pioneers +emerging leaders in the years to come? What might we achieve together?

Well, we have a big opportunity to get that 15 percent happening. Current levels of leadership, both in recognised positions and as change makers, are so low that there is no shortage of work to be done. Jump on board!

You can read more here:



https://disabilityleaders.com.au/

# Standing on the shoulders of giants – the development and growth of lived experience workers

#### **Meet Tim Heffernan**

Tim Heffernan has made a huge contribution to the lived experience movement in mental health over many years. While he holds an impressive array of professional roles relating to this, such as Deputy Commissioner at the NSW Mental Health Commission and Peer Coordinator at SENSW PHN, his twitter bio sums up Tim, the leader and mentor who I know and admire best...

"poet, peer worker, tending gardens that are my own planting, just like my posts."

A kind, generous and considered human, whose consistent, steady voice advocating for lived experience to be at the table, to be recognised for the immense value they bring + his unwavering passion for the development and support of the peer workforce, has played a huge role in this important work gaining recognition and traction over the years.

A talented poet and founder of Mad Poetry at the 2016 Wollongong Writers Festival + Co-editor of the Clozapine Clinic - the Frater Project - Verity La.

I spoke to Tim about what makes him tick, all that he has learned during his commitment to the lived experience movement and his vision for the future of 'nothing about us without us'.



#### Tell us a little bit about yourself Tim + how you came to be doing this important work. What is your why? What sits at the heart of all that you do and is the reason that you keep on going?

I grew up in rural and regional NSW, moving to Sydney in 1978 to complete my teaching qualifications. I taught in a Catholic Boys school in Albury for just over a year before resigning on the day I chased the Math Head Teacher around the playground with a fire extinguisher.

By the end of that year, 1983, I was admitted to the Wagga Mental Health Unit with an apocalyptic psychosis that centred on Ronald Reagan, the Cold War and a little-known nuclear threat called Able Archer, Typically, I was medicated and diagnosed with Paranoid Schizophrenia. This diagnosis was changed to manic depression (bipolar) a year later with a different medication.

Following a longer admission to Kenmore Hospital in 1985, I resumed my teaching career at a public high school six months later. I taught English and History for another nineteen years, married and became a father to two beautiful girls. My teaching career ended in 2005 with another admission to the Wollongong Mental Health Unit. I then worked as a disability support worker in a large group home for people who required higher levels of care.

My entry into the other world of mental health began as a volunteer Rural & Regional Ambassador with the Black Dog Institute in 2007 and then as a Consumer Rehabilitation Assistant with Illawarra Shoalhaven Local Health District in 2009. It wasn't long before we adopted the name Consumer Worker and then Peer Worker. I moved into my present positions with the Primary Health Network (PHN) in 2017 and as a Deputy Commissioner in late 2018.

Why do I do this work? I am motivated by a deep belief in social justice and human rights. I am motivated by the people we have lost along the way. I am motivated by my own experiences of coercive and involuntary treatment, by the experiences of seclusion, restraint and treatment that stripped away my hope as a young man.

I am motivated by my belief that people can live good lives despite the experiences of distress and disconnection that come from seeing the world differently.

I am motivated by the way in which people who have been 'diagnosed' by the system connect with this world and with each other. At the heart of all this is people.

I keep going because I believe that peer work can change the coercive, involuntary, overly medicalised constructs that we have come to know as the 'mental health system'. I believe that relationships between people, rather than power exercised on people, can allow people to build wonderful lives despite experiencing the distress that comes from living in such a complex world. Sometimes it is very difficult to keep going and at those times I trust my family and friends to keep me on the pathway forward.

# The growing opportunities for people with lived experience to work with services, organisations, and governments, didn't just magically happen. Could you tell us a bit about the mental health advocacy movement?

The consumer movement developed alongside the civil rights movement in the 1960s. People were moving out of institutions, and they came together for support and friendship. Issues of discrimination and stigma that kept them in poverty and out of employment and adequate housing, saw people joining together to challenge a coercive and powerful system. In Australia, things gained momentum in the early 1990s with the development of a National Mental Health Strategy which was crucial to the development of consumer rights, participation and workforce. Following this, States developed Consumer Advisory Groups.

In the absence of a funded National Mental Health Consumer Peak, strong support for the Lived Experience (Peer) workforce development has come from our state peaks BEING, VMIAC, CoMHWA, LELAN and the ACT Mental Health Consumer Network. The state peaks have endeavored to fill this space by forming the National Mental Health Consumer Alliance.

In NSW the Peer Workforce had its beginnings at Rozelle Hospital in 1993 with the Consumer Consultants Project led by Helen Blum. Two years later, Peter Schaecken led the first community advocacy and participation service. The first NSW Consumer Worker's Forum organised by Sandy Watson was held at Rozelle in 1998. The Consumer Workers Forum became the NSW Consumer Workers Committee in 2012.

In the NGO sector, peer workers were employed in the Personal Helpers and Mentors program (PHaMS), Housing and Accommodation Support Initiative (HASI), and Day to Day Living (D2DL). Flourish Australia have led the development of the peer workforce with their 'Why not a peer worker'. With the demise of block funded programs like PHaMHS, HASI and Partners in Recovery, most NGOs have developed models of peer work that can serve people under the NDIS. A new classification, the Recovery Coach is also seeing many peer workers providing peer support as sole traders. It is confusing and the workforce is vulnerable.

At a Commonwealth level, PHNs are becoming increasingly influential in commissioning peer work and in providing support and development opportunities to the peer workforce. My own position in South Eastern NSW PHN is a concrete example of how PHN's can provide regional leadership for the peer workforce. PHNs are tasked to implement the recommendations from the 5th National Mental Health Plans and so will have responsibility for the implementation of the National Peer Workforce Development Guidelines. The PHN Mental Health Lived Experience Engagement Network is working to support the development of the peer workforce in primary health, as well as ensuring optimal consumer and carer engagement in our commissioning work.

#### What does 'nothing about us without us' mean to you?

The saying, 'nothing about us without us' is a powerful reminder that some groups in society have come from the opposite context, where everything about them happened without them. It reminds us that people must continue to speak out for the right to have control of their future. It is a powerful statement in the context of the mental health consumer movement. just as it is in the disability rights movement.

I think it is important to understand that the slogan was adopted by people with disabilities in the drafting of the Convention on the Rights of People with Disabilities and that it continues to guide the implementation of the Convention. It is a matter of law that people with disabilities are involved in the drafting, development and implementation of legislation and policy and in all decision-making processes affecting their lives. The slogan demands that 'involvement' is genuine collaboration and co-design through lived experience leadership.

Unfortunately, when I hear the slogan, I am constantly reminded of how far we still have to go to achieve 'nothing about us without us.' I think of our workforces and organisations where people with lived experiences are largely absent from leadership and management positions, of the Mental Health Acts that are designed to control us, of the treatment environments in acute mental health units which we seek to change but can never really achieve that change and of the obstacles that are placed in front of us by stigma and discrimination. Thankfully though, the slogan is a rallying cry which brings us together, unifies us and allows us to take strong collective action to correct a system and society that has 'othered' and excluded us.

#### What did such work look like when you first started out, and what changes have you seen over time?

I began Lived Experience work as a Consumer Rehabilitation Assistant in a Community Mental Health Rehabilitation Service in Wollongong. These positions came from an innovative project that began as the language moved away from rehabilitation to recovery. We worked with consumers one on one, in groups and as part of a multi-disciplinary team, but I think the term 'assistant' positioned us as less than the clinical workers. I was lucky to become involved in the NSW Consumer Workers Committee as we drafted the NSW Public Mental Health Consumer Workers Framework, and I witnessed a substantial growth in the public health consumer workforce.

Language has certainly changed over the years. We moved from Consumer Worker to Peer Worker in 2014/15 with the drafting and release of the Certificate IV in Mental Health Peer Work. I think this created some confusion about consumer and carer roles in mental health. We are now moving into the language of Lived Experience. Job titles have evolved with the language change – Consumer Worker became Consumer Peer Worker and is becoming (Consumer) Lived Experience Worker.

We are on the cusp of significant and positive change in 2021. We will soon see the release of the National Peer Workforce Development Guidelines and the probable formation of a National Professional Association for Peer Workers. It also looks like we will have a National Mental Health Consumer Organisation. Separate from national approaches, we are also seeing change at a state and local level. I am very proud of our local, South Eastern NSW Peer Work Framework. The structure will enable serious and planned investment in peer work, replacing the piecemeal approach we have experienced to date.

#### Aside from yourself, who are the key lived experience leaders to which we owe a debt of gratitude?

I'm reluctant to name names at the risk of leaving out so many amazing leaders, but I will say the name of my dear friend Fay Jackson has been there from my first day of training at Black Dog Institute in 2007. I have had the privilege of working with her at the Commission and at Flourish Australia. Fay shaped a whole organisation around peer work and her influence within the Commission has helped set peer work as a state priority within mental health treatment. She also laid the foundations for the peer workforce in the Illawarra and Shoalhaven Local Health District. Fay has always inspired and supported me.

Right now, all the names of the lived experience leaders are scrolling through my mind – what champions!

#### What are you most proud of in your work in this field?

I'm proud of working with so many incredible human beings. I love the connections that come from peer work, and I love to witness people move from distress to lives that are rich and thriving.

#### Where would you do things differently if you had your time again?

If I had my time again, I would have advocated for more hours sooner. I began on 8 hours a week and needed to keep my disability carer job for five years until I got something close to full time. It seems I have always juggled several jobs at once, and I have certainly learned that this is not always healthy. Mind you, I loved my Disability Support work.

#### Is there anything that you feel has held the movement back?

I think the confusion of consumer and carer identified roles has caused problems. I'm of the belief that consumer workers are peer workers, in line with most countries, and that carer identified workers,

who are incredibly important, should have a different name to peer. But I think the horse has bolted on that one.

I think we have been seriously damaged through the lack of a National Mental Health Consumer Organisation. The lack of this representative systemic advocacy has allowed those in power to position the movement as fractured, divided and unrepresentative. It has allowed the system to divide us.

#### What has been its greatest strength?

The incredible people who have always made up the movement. It is often said that we stand on the shoulders of giants.

#### How do you mentor and support new people starting out in this space?

As a peer. We have a mutual and reciprocal relationship. I have lots of phone conversations. Lots of emails. We support each other informally, but this is often the most powerful support. I think opportunities to get together, like through the NSW Consumer Workers Committee's Annual Forum, through attending conferences like TheMHS or through involvement in the PHN's Mental Health Lived Experience Engagement Network are golden.

In South Eastern NSW, we have created three Peer Worker Networks that meet regularly for networking, co-reflecting, peer support and professional development. Except for Covid times when we Zoom, we meet in Wollongong/ Nowra, Queanbeyan/ Goulburn and Bega/ Batemans Bay. All peer workers (public, NGO, independent) can attend, and every meeting is rich and powerful. Our Regional Peer Work Framework was only possible because of these networks.

#### If you could give developing + emerging leaders one piece of advice, what would it be?

Understand where we have come from, know those who have been there and walk with those who are going in the same direction. This is about us remember. Nothing without all of us.

#### What are the opportunities for the pioneers + emerging leaders in the years to come? What might we achieve together?

Prepare to take on leadership within new systems and learn how we can co-produce these new places. Develop allies. We can lead but we need to bring people with us into a transformed system. Let's tell the truth about what has happened and let's provide the space for reconciliation. Let's then move forward.

# Listening to and learning from lived experience is the foundation for a better future

#### **Meet Ingrid Ozols AM**

For over 21 years, Ingrid Ozols AM has been a tireless advocate in the mental health and suicide prevention workplace, community and academic sectors.

Over this time, Ingrid has drawn on her direct and indirect experience of mental health and suicidality to address stigma and work towards change by championing the voices and experiences of those who are no longer here to have their lives and trauma acknowledged and validated.

Ingrid has inspired and educated more people than she could ever know. She personifies the phrase 'speak the truth even when your voice shakes', often at huge personal cost and sacrifice. She continues to step up, include, mentor and welcome fresh voices and emerging new leaders.

Thank you Ingrid for sharing your story, your wisdom, your lessons and your hopes for the future with us.



#### Tell us a little bit about how you came to be doing this important work.

Having a mental health vulnerability myself, surviving suicide attempts, caring for loved ones with similar vulnerabilities - I know how important change is.

Navigating the mental health system, experiencing the stigma and shaming firsthand, I am one of the blessed few to have also had experiences of great and, in fact, lifesaving mental health care and support.

When "well" and "functioning" I found that I could use my experiences to stand up for change change in the way society thinks and talks about trauma pain, mental health, human vulnerability, suicide.

#### What did mental health advocacy look like when you first started out, and what changes have you seen over time?

We have come such a long way. There are more opportunities for change - and much needed change is coming faster because of covid. These days, we are having braver conversations, we know more (still not enough), and there is a little less stigma in some parts of the world. I wish we could have had the knowledge and the resources we have today, a lifetime ago.

Society was doing and still trying to do the impossible. Pretending humans can segment the personal from professional/work parts of our humanness, our lives - kidding ourselves for forever that the two could be separated.

#### What are you most proud of in your work in this field?

Starting conversations about workplace mental health. In the early 2000's I was honoured when Telstra corporation invited me as an advocate to take a blank canvas and develop a strategic plan on creating and implementing a national company-wide mental health and wellbeing strategy.

It was the start of a revolution. Bringing the mental health sector to the corporate table – and vice versa, through sharing my lived experience from illness to wellness. It was most rewarding to be a conduit bringing industry and health together, and encouraging dialogue that both sides could understand to help support each other.

Starting my consultancy. Mental Health At Work (mh@work) - many people from family, friends, colleagues – laughed, laughed at me for thinking I could do this. They said: "Why would anyone want that?" Here's why - over the years, I've had the honour of developing the first online mental health workplace training program in the world, as well as pictorials, books, collateral for the first Australian workplace campaigns... all from the lived experience perspective.

Being part of new conversations. Particularly ones that were uncomfortable at a time when few wanted to hear the messages. I'm proud that I just believed-believed-believed that no matter how much my body was shaking or how sick with terror I would sometimes be, that I was called to be vulnerable and hopefully help someone else in this situation to navigate their path more supported and less isolated – to give to others what I wish I had received, what could have helped my loved ones earlier.

"People laughed at me when I was bringing mental health and suicide prevention into the workplace... "who would talk to me about this? What was I thinking?" ...Now 20 years on the landscape has changed. There is legislation now! Wow. It happened! It's real and being taken seriously. It's not being whispered about."

#### What about your work lights you up?

Creating, building, and facilitating peer support, consumer and carer groups; participating in local, state and national policy development, co-production, research and peer work; enhancing workforce capacity and capability nationally and in Victoria.

Supporting loved ones, colleagues and the countless people I have met through this work.

The hugs, the laughter and the tears.

#### When working with people who are experts by lived experience, what are the most important baseline factors that organisations need to get right.

- Creating a safe, supportive and trusting culture
- Acknowledging and embracing humanness including our diversity and vulnerability
- Valuing the contribution, knowledge, skills, time, effort and emotional investment through supportive actions, resourcing and fair/appropriate remuneration beyond vouchers, lowest pay rates possible, or expecting pro bono.

#### What do we stand to gain as a community by building meaningful opportunities for governments and organisations to really listen and work in partnership with people with lived experience?

- Healthier communities that are willing and able to come together and support each other
- Improved products and services with richer outcomes
- People and communities able to contribute and live fuller more meaningful and enjoyable lives
- A world that embraces vulnerability, diversity and that appreciates the complexity of humanity and relationships.

#### Is there anything that you feel has held the mental health lived experience movement back?

At times, over the years, I've seen egos and self-interest get in the way of progress, members turning on ourselves and not supporting each other. I've seen nastiness, bullying and an unfortunate 'us and them' tension around who is 'allowed' or has 'enough' of a lived experience to be entitled to have a voice. This behavior (often due to unresolved traumas) can further traumatise and trigger others, making it feel unsafe for them to contribute or participate.

I believe that we are stronger together so I find it disappointing to see parts of suicide prevention lived experience movement positioning what they are doing as new when it is on the shoulders of those who came before us that we all stand today. This is unfair, disrespectful and divisive.

#### Who do you really look up to in the advocacy and leadership space?

How blessed am I to be struggling to answer this question! A lifetime of people and relationships have ebbed in and out of my story, quietly, not so quietly, joyfully, painfully, authentically and not. All have left me with something.

If you could give developing + emerging leaders any advice, what would it be?

- Stand up for what you believe in
- Never give up keep standing up for what is right not what is easy
- Balance the ability to share your perspective but also to listen to others and compromise if needed.

**The future is better together**... My intention is to foster and encourage new fresh voices, perspectives & energy to the table, to nurture future leaders and new ways of 'doing', in order to take on the challenges that lie ahead.

#### How do you mentor and support new people starting out in this space?

Ideally with chocolate, laughter, hugs and purpleness. To help them stand up, even if sh\*t scared, knowing their backs are supported. It is time to change the narrative, giving the new guard confidence to grow the movement widely and more inclusively.

"Togetherness", is about sitting in discomfort, having painful conversations, laying aside combativeness and instead addressing power imbalances in all guises. Corralling, all of community, irrespective of occupation/vocation/title, to respectfully acknowledge and validate opposing life experiences.

"Nothing about us without us" is about all of us.

I hope to leave the world a better space that I came into - with more loving and way less stigma.

"I am proud that I have helped to change the conversation nationally and internationally. Proud I used my voice all those decades ago to bring human, unsexy, polarising conversations into the community and board rooms when no one else was willing."

# Trailblazing change for migrant and refugee inclusion

**Meet Arshdeep Cheema** 

Smart, passionate and determined to make a difference, Arshdeep Cheema was born in India and migrated to Australia at the age of two. As a Public Health professional, Arshdeep is an advocate for improving health access for migrant and refugee communities. She draws from her personal and previous professional experience as a public speaker and representative on multiple advisory groups that promote refugee and migrant inclusion. Through her advocacy, Arshdeep aims to shed light on taboo topics such as women's reproductive health and family violence, but ultimately her life's goal is to leave a positive impact on the world through sharing her story and uplifting others to do the same.



#### What lights you up about your work, and why does it matter so much to you?

I've often been a sensitive person and a person of action. It's important to me that when I see something that I don't like, I do something about it. Years of being a bystander that couldn't do anything has left me as a passionate advocate for the rights of minorities and women, because ultimately, I can't wait around for someone else to make change.

#### Stepping up and starting out in this space takes guts and tenacity. Do you have any mentors or people that you look to for peer support, advice or inspiration?

I could never attribute my confidence or my motivation to keep pushing forward to one person, but if I had to, it would be my mother. She may be the person that I clash with the most, but at the end of the day, she's the reason I'm the outspoken woman I am today.

#### What does 'nothing about us without us' mean to you?

It signifies the need for community-based change to include the community itself. Too often we see programs that are for specific groups, that do not actually take the needs for that group into account. How can we make effective change when we don't include the group that has the most important input?

#### What do we stand to gain as a community by building meaningful opportunities for governments and organisations to really listen and work in partnership with people with lived experience?

The biggest advantage of this work becoming commonplace is that a lot more individuals would be actively participating in the NGO sector. I think it's disheartening when people are taken on by organisations and governments, in order for them at the end of the day to say "see, we're doing something", when in fact those individuals are not part of the decision-making process.

There is a need for a variety of individuals with lived experience to be given meaningful opportunities where they can see the outputs of their labour.

## What do we stand to gain as a community by building meaningful opportunities for governments and organisations to really listen and work in partnership with people with lived experience?

The biggest advantage of this work becoming commonplace is that a lot more individuals would be actively participating in the NGO sector. I think it's disheartening when people are taken on by organisations and governments, in order for them at the end of the day to say "see, we're doing something", when in fact those individuals are not part of the decision-making process. **Rather, there is a need for a variety of individuals with lived experience to be given meaningful opportunities where they can see the outputs of their labour.** 

## What are the challenges and barriers that need to be overcome for meaningful engagement? What makes you feel safe and able to contribute?

Often as young person, my presence in an advisory capacity is generally tokenistic. In an age where there is an evident need for youth to be informed on political issues, we also feel the need to contribute and be taken seriously. In order to make sure our voices are heard, the best thing to do is listen, and take our experiences into account, and if possible, elevate our voices.

# "We can't be the leaders of tomorrow, if our voices aren't heard today."

#### What are your hopes for the future of working with people who are experts by experience and how can the 'old and new' waves of leaders be stronger together?

I hope in the future, that collaboration between the old and new waves of leaders can be much stronger than it is currently, as there are valuable contributions that can be made from both parties. It's evident that the addition of new wave leaders can provide input on current issues, whilst the old wave can provide solutions based on valuable experience.

Ultimately, there is a need to acknowledge the assets that all advocates and leaders have and how we can now work together to create change.

Find out more about Arshdeep's work, at:



in linkedin.com/in/arshdeep-cheema-b40346194/

# What works in one community may not work in another – understanding the needs of Aboriginal and Torres Strait Islander people

#### **Meet Tiarnee Schafer**

Tiarnee Schafer is a proud Kalkadunga Kintja from Mt Isa QLD who is currently living in Sydney working at the Black Dog Institute as the iBobbly Project Officer and Social and Emotional Wellbeing Community Liaison. She graduated with a double degree in Psychological Science and Business.

After finishing high school, Tiarnee started to notice the high rates of suicide in her community and saw the effects it had on her community and family. She wanted to help her mob and thought the best way to do that would be to study Psychology, which saw her move to Brisbane and attend Griffith University. After completing her Bachelor's degree, Tiarnee has continued to study a Master of Suicidology and is currently completing her fourth year in psychology studies.

Tiarnee's lived experiences have made her passionate about improving the social and emotional wellbeing within her community and the broader Aboriginal and Torres Strait Islander community. She wants to make a difference by gaining a better understanding of best practice in suicide prevention.

#### What lights you up about your work, and why does it matter so much to you?

This work is important and matters to me as I am passionate about self-determination and having mob from all walks of life, voices and stories heard, as everyone deserves to have their voices heard. Having different perspectives means local needs are heard, and local solutions can be implemented. **What works in one community may not work in another.** 

It's not fair that just because you come from a small rural or remote community, your needs cannot be heard.



As for me, being on a journey to becoming a qualified Psychologist is important to me as I want to create change and help mob who are experiencing hard times. One way I can do this is by decolonising the ways we work and incorporating Aboriginal ways of knowing, being and doing to give back and help mob.

We are the oldest living culture; we should be the oldest living people too. I want to bring back hope, inspiration and opportunities to those who previously haven't been given the opportunity to have their story heard and listened to.

### Stepping up and starting out in this space takes guts and tenacity. Do you have any mentors or people that you look to for peer support, advice or inspiration?

I am lucky enough to be surrounded by incredibly staunch blak women. I always look to my mum and grandma for inspiration. My grandma didn't have an opportunity to go to university, so I make the most of these opportunities when they come my way. This is something she never got the chance to experience. Secondly, my mum, because she worked three jobs to put food on the table for my siblings and I, showing me the definition of resilience and a great work ethic. Thirdly, Tanja Hirvonen, whom I am lucky to have mentor, guide and support me on my journey to becoming a psychologist. She also happens to be a Jaru and Bunuba Clinical Psychologist. In the Lived Experience space, I also really admire Leilani Darwin's work and advocacy; not only has she shared her story with mob, so they then know that they are not alone with what they are going through but also her commitment to lived experience has been critical in the acknowledgment of the Aboriginal and Torres Strait Islander Lived Experience getting a voice at the table as it deserves.

#### What does 'nothing about us without us' mean to you?

'Nothing about us without us' to me means everyone's voices have been heard and included in whatever it is you are working on from the get-go. It means that our elders, our young people, LGBTIQ+SB people and those from different geographic regions have been included from the start. Better yet, Aboriginal and Torres Strait Islander peoples are leading these projects and initiatives. It means fighting for self-empowerment and self-determination and decolonising how we work until 'nothing about us without us' is the new norm.

### What are the challenges and barriers that need to be overcome for meaningful engagement? What makes you feel safe and able to contribute?

Changing how we work by using a co-design process and not a tick box approach. To meaningfully engage with Aboriginal and Torres Strait Islander peoples means listening and engaging through a decolonised way that is trauma-informed with Aboriginal and Torres Strait Islander peoples and communities needs and interests at the forefront. Meaningful engagement takes time, trust and full commitment.

It's about being genuine and not tokenistic.

We need to acknowledge and privilege Aboriginal ways of knowing, being and doing and listen to what Aboriginal and Torres Strait Islander peoples want and have to say. Diversity and inclusiveness isn't about having one Aboriginal and Torres Strait Islander person at the table speaking for everyone, it's about having multiple people at the table. There are hundreds of different clan groups across Australia, and we need diverse and unique perspectives from different walks of life.

"You will know when you have meaningfully engaged as the people and communities will tell you so. It's not for the service/ organisation to decide if it's been done meaningfully. So overall, don't consult, co-design with mob. "

To feel safe, the environment needs to be culturally safe and contribute through different forms such as yarning, artwork and poetry. For me, I need to be able to feel acknowledged and respected. I need to feel like I am making a difference and not contributing through a tick box approach.

What are your hopes for the future of working with people who are experts by experience and how can the 'old and new' waves of leaders be stronger together?

I hope that lived experience comes first. The way forward involves recognition of power inequalities and action to shift unequal power. This cannot be just written in a document - there needs to be accountability. I hope that spaces are safe and non-judgmental for people to share their stories and wisdom to deepen views and ways of working to a more meaningful and inclusive space in the future.

It's time we shift who is at the table making decisions and leading conversations; we are here, capable and ready. This is our lives, we live and breathe them every day, it is not a 9-5 job for us. There should be no excuses; we have plenty of Aboriginal and Torres Strait Islander peoples capable and willing to step up and take the lead. We need to raise the bar and set this as a new standard for best practice - by mob, for mob.

Find out more about Tiarnee's work, at:



linkedin.com/in/tiarnee-schafer-8426aaa5/

# People with a lived experience have a PhD in getting better – using my brain injury recovery to inform change

**Meet Eva Sifis** 

Eva Sifis is a force to be reckoned with – a change maker and leader in the disability space who has lived and is living a colourful life. Travelling the world as a professional dancer, in 1999 Eva experienced a severe brain injury, and has since had to rebuild her life. Eva describes herself as having a "PhD in getting better" and works tirelessly to use her unique insight into living with disability to influence change and make a difference.

Eva's channeled her drive, determination and self-belief into her recovery, and today she remains both passionate and curious about what makes us all 'better'. Utilising her discoveries Eva has built Australia's first and only peer initiated, developed and led training for people with an Acquired Brain Injury (ABI), By  $Accident^{TM}$ .

From advocacy to advice, Eva contributes to the work of Voice At The Table, Small Business Victoria, Women with Disabilities Victoria and the Australian Federation of Disability Organisations (AFDO). At the heart of everything she does is encouraging organisations and decision makers to include people with cognitive disabilities when developing policies or making decisions that impact the disability community.

Eva has blended her artistic practice with her lived experience and is currently producing and appearing in a theatrical work celebrating how life evolves after a brain injury – Pieces Of Me.



### What lights you up about your work, and why does it matter so much to you?

When I started carrying out my recovery from Severe Brain Injury in 1999, I only heard from the professionals around me. It was some years before I had a close friend who also had sustained an injury. I remember the sense of kindredship it gave me and I do believe this assisted my forward movement. Having someone understand and respect your trials is a source of strength.

Acquired Brain Injury (ABI) is a very isolating experience as changes generally occur to one's personality, which is where the seat of most friendships lies.

I started By Accident recognising that we who have gone through this complete life shakeup are authorities of our own experience. I know the difference being heard makes, and providing a platform for others to share their experience gives me a sense of completion.

## Stepping up and speaking out in this space takes guts and tenacity. Do you have any mentors or people that you look to for peer support, or inspiration?

Seeking mentors from the very beginning of my second career, disability arts, I have worked with them consciously and constantly. It has developed much of my progression in all facets of my life, not just job-related.

### What does 'nothing about us without us' mean to you?

As one of the subjects covered in the Voice At The Table training I deliver, it is a very familiar phrase. In fact, being a member of one of the most marginalised groups of the disability sector, that of the cognitively disabled, Nothing About Us Without Us is essential to making sure our voices are heard, our access needs attended to, and our people respected.

### What do we stand to gain as a community by building meaningful opportunities for governments and organisations to really listen and work in partnership with people with lived experience?

We stand to gain compassion and humility.

These two strengths are sorely lacking in society today. Is it a pipe dream to think the Government could lead by example? Through my work with Voice At The Table, I know at least some departments are listening.

It is my dream to be taken seriously for the value I have to offer.

I just don't want to hold 6 positions to do so!

## What are the challenges and barriers that need to be overcome for meaningful engagement? What makes you feel safe and able to contribute?

The elephant in the room are the models of disability followed by Australia. Where does the power lie? Who gets to influence assumptions held widely?

This country remains largely a Medical model (the power with doctors and hospitals), but there remain some vestiges of the Charity model (charitable organisations benefiting off the public's handouts for the poor crippled). This is just icky in these days and times, however we have an extremely conservative government lacking a social justice lens. Countries like the UK and even the US long ago changed to the Social Model of disability (where the person is disabled by attitudes and built environs about them), but the new kind on the block is the Human Rights Model (that respects the inherent dignity of the person first) and this makes me excited.

Now just to get our policy makers on board!

What are your hopes for the future of working with people who are experts by experience and how can the 'old and new' waves of leaders be stronger together?

This is where the power of the future lies. By acknowledging the worth and salience of lived experience, we can move forward armed by life lessons respecting what it has taken to learn them.

"It is my dream to be able to strip back By Accident and offer the structure to other people with Brain Injuries who, like me, have researched and experienced their way through the experience and they, too, can take others through a curriculum supported by their experiences and learnings."

Find out more about Eva's work, at:



## Put your ego aside, there is always more to learn Meet KC

The future certainly looks bright when you get to spend time with change makers and extraordinary advocates like KC and learn about their work as part of Y-Change - a social and systemic change platform for young people with lived experiences of socioeconomic disadvantage. KC and this exceptional group of humans work to challenge the thinking and practices of social systems through advocacy and leadership.

As a consultant on the Y-Change team, KC uses their lived experience and expertise to pursue a career in workshop facilitation, peer mentoring, academia and general activism. This lived experience includes, but is not limited to, being neurodivergent, queer, non-binary and disabled. They are currently studying a Bachelor of Education Studies with the ambition of reinventing current systems (such as education and mental health services) to be more inclusive and accessible.



Visibility and representation for marginalised communities underpins everything that KC does. Their passion for building a more empathetic and healing society is infectious and shines bright!

Knowing they are sitting at decision making, policy making and change making tables, working towards systems change, social change and a deeper understanding of the social issues that affect young people, is a very reassuring thing indeed.

### What lights you up about your work, and why does it matter so much to you?

I honestly can't imagine doing anything else with my life. I have a lot of trauma from my past, and while I don't subscribe to the concept of "everything happens for a reason", there's nothing more fulfilling than the idea that I might be able to work towards a better world for the next generations.

### Stepping up and starting out in this space takes guts and tenacity. Do you have any mentors or people that you look to for peer support, advice or inspiration?

Absolutely! I am so privileged to have a very strong support network. I receive unending support and inspiration from Lauren Oliver, Morgan Cataldo and the entire Y-Change team. Also, a huge shout out to Russ Pirie from Merri Health – I would not be where I am now without his unwavering faith and support. I also strongly believe that mentorship is an equal exchange. I like to think that I offer my own wisdom and inspiration to my mentors, just as I am constantly learning and drawing inspiration from the young people that I mentor - particularly the participants of YGLAM (queer youth theatre ensemble).

### What does 'nothing about us without us' mean to you?

The concept of 'nothing about us without us' – coined by disability rights activists – is at the core of everything I do; the most effective way to implement meaningful change is to listen to those with lived experience. As my fellow Y-Changer Kirra has said, "You wouldn't ask a dog what to feed a cat".

### What do we stand to gain as a community by building meaningful opportunities for governments and organisations to really listen and work in partnership with people with lived experience?

Everything! When we work towards building a more empathetic and compassionate society, rather than focusing on what brings in capital, we start to build systems that are more broadly accessible and inclusive. This in turn creates stronger and more effective communities.

### What are the challenges and barriers that need to be overcome for meaningful engagement? What makes you feel safe and able to contribute?

People can really underestimate the mental and physical toll that constantly rehashing past trauma can have. It takes time and skill to be able to safely navigate work as a lived experience consultant/ expert. For me, this is achieved by having a strong support network, the freedom to be able to take time away from work when needed, and lots of therapy - but it's important to acknowledge that it is a huge privilege to be able to access these things.

### What are your hopes for the future of working with people who are experts by experience and how can the 'old and new' waves of leaders be stronger together?

This question feels very salient to me, as someone who is currently too old to be considered a "young person" but too young to be considered an elder. I've thought a lot about this and fundamentally I hope that in the future, we are much better at putting our egos aside and knowing that there is always more to learn – and also that there is no "correct" way to learn or to teach. I hope that there is more cohesion between leaders; both generationally, and in terms of lived experience experts and academic professionals.

Find out more about KC's work, at:



https://linktr.ee/AceCaptainKC

and about Y-change here

"For myself personally, I am excited by the idea of becoming a queer, non-binary, disabled elder simply to show other queer, trans and disabled folk that there is a future for them, which is something that I really could have benefited from when I was younger. At the same time, I hope I remain humble enough to be able to step aside and learn from new generations."







### Welcome to the 2021 working with survey

## Have you been part of a project or role that involved lived experience engagement or leadership? What was it like for real?

Across a variety of sectors, projects (and work) that involve partnering and 'working with' people with lived experience have become increasingly popular (and promised by organisations). But experiences, practices, and practitioners within such projects can vary. We want to go deeper than buzzwords and find out what's really happening from the point of view of those who are in the thick of it.

#### Who are we?

This survey was pulled together by *The Better Together Collective* and a cross-sector group of friends of working with.

### What do we mean by 'working with'?

**Working with** is an overarching term we use to describe the many ways in which governments, services, organisations engage, include, and work in partnership with people who have firsthand experience of the problem to be addressed, in order to drive positive social change. Doing with, rather than doing to or for.

Names such as: lived experience led approaches, partnering with consumers and carers, participatory approaches, lived experience engagement, consulting, co-design, co-production + cocreation, consumer-led, by mob for mob, community-led, by people for people or similar.

Might include being part of: co-design workshops, document reviews, program evaluations, a committee or Consumer Advisory Group, testing products or resources, focus groups, consultations, peer workforce, and many other things not listed here.

We want to start a conversation with people who have been part of working with projects, either by representing the voices of lived experience or in other roles.

We want you to tell us how it really is!

#### Help us make something we can all share.

A baseline snapshot of 'the state of working with' will be published for community benefit in the next issue of with us e-zine. So that those of us who value this work have something to build upon, as we all work in different ways towards raising the bar and improving the quality and consistency of working with.

### How long will the survey take?

- We think it should take about 5 -10 minutes to complete.
- There are two sections, containing mainly multiple-choice questions and a few free text fields.
- Section 1 has some quick demographics to help us get a picture of the broad range of people doing this work.
  - Section 2 asks about the experience of being part of working with projects or activities.
- All personal information will be kept private we will not share your name or contact details at any stage. The public snapshot will contain general data and themes. This may include sharing words or quotes, but we will not be sharing any information that identifies you in any way.

### Rather talk to someone? Or need something extra to be able to complete the survey?

No problem. If you send an email to hello@bettertogethercollective.com we will email you back and see if we can help.

Take the survey here:



https://forms.gle/nY8twTjKctWqr9m49

## Language Matters

### with Sonia Sanchez Moreno

Sonia Sanchez Moreno is the founder of <u>Sylaba</u> <u>translations</u>.

As someone who has experienced her plain language training firsthand, I can tell you that her passion for effective, culturally appropriate and inclusive communication shines through every step of the way. She has a wonderful, practical, clear and actionable style which is backed up with her extensive experience as a veteran of scoping, planning and executing multilingual translation projects to help organisations build relationships with their audience.

A bright ray of light in the translation space, we asked Sonia to tell us a bit more about herself and why her work is so important. She also shares some great tips and information for organisations to consider when developing accessible and culturally appropriate communications and translations for the community.



### Tell us a little bit about your story, and how you came to founding Sylaba?

I came to Australia in 2014 with 6 years of translation-specific studies under my belt and the experience of having migrated twice and the challenges and learnings that came with that.

After working in the community translations industry for about 3 years, I realised the industry was missing empathy, human touch and translation theory in equal parts.

I realised that providers in Australia tend to focus on word counts and turning projects around as quickly as possible. Not really caring about the impact their work has in migrant and refugee communities.

Sylaba was born from an effort to do the right thing. Translations are expensive enough to not be done effectively. And for them to be effective, we need to put the community at the center of the process. That means questioning how the English is written, whether it's accessible, culturally appropriate and even respectful of a given cultural group or religious belief.

### What about your why - what makes you so passionate about the work that you do?

Knowing that somewhere in Australia, someone might pick up a fact sheet today and feel cared for. For people in situations of stress to feel that someone somewhere produced a resource that is helping them feel better about the journey ahead of them: whether it's a cancer diagnosis, a child with autism or a spouse with dementia.

Migrating and being far away from family and friends is hard enough.

### Is there a project, a body of work or a personal achievement that you are most proud of?

I am fortunate enough to have been involved in quite amazing projects since the origins of Sylaba. If I was to name just one, it would be the work that I did with the Australian LGBTIQ Multicultural Council with their very first translation project.

Translating LGBTIQA+ information is a very complex process as it's a highly sensitive topic very much linked to religion and deep cultural beliefs. So, we had to do a lot of groundwork to come up with translations that were culturally appropriate and yet respectful of the LGBTIQA+ communities we were trying to reach.

### I love the description of your approach around supporting organisations to build relationships with their audience. Why is this so important and what changes when organisations start to see the value of this?

I am a strong believer in translations as the means to an end rather than the end itself. The difference between translating to tick a box and translating to communicate.

When organisations really care about their audiences genuinely understanding what they are trying to communicate, that's when they realise that for the community to listen it's important to build a level of trust. Because migrant and refugee communities bring with them a long history of distrust of government and public service caused by corruption, war, persecution...

When an organisation realises that for their audience to understand, they have to be the ones doing the understanding first, that's when the magic happens. When that relationship of trust is built, that's when organisations start to learn enough to communicate with people in the language people need to hear to be receptive. And not the other way around.

## What do you wish orgs/governments/services would understand when it comes to creating their campaigns, products and resources?

CALD communities are not all the same. Each community is different. I often see two parallel campaigns: one for mainstream Australians and another one for CALD communities. Effectively, that just means that a Greek family that has been here for 40 years will be approached in the same way as a Burmese family who have just settled in Australia.

I also wish there was a wider understanding of plain language and how important it is as a foundation to anything produced with public money. I am sick and tired of getting ATO letters that I can't understand. Because if I don't... what hope does a newly arrived refugee have?

### What are the key considerations they should make before they even begin?

Understand your community. Take the time to talk to them, understand their literacy levels, their existing knowledge and the potential cultural barriers that might clash with the information you are trying to present to them. And be strategic about it all. Really, all I want is for organisations to genuinely care. Because if they care, they'll do the right thing.

What are the main barriers that people who are multilingual experience when trying to navigate mainstream communications? What are the basics that make it easier?

Trust, culture, systems, language.

Clear communication (plain language) goes a long way, whether it's spoken or written. Seeking help can be a big step when you are newly arrived and have no social supports. If the help you get doesn't align with your literacy levels or existing knowledge, it's completely useless. This experience can be a barrier in itself.

### Are there any great articles, resources or sources of information that our readers should know about? (especially any that you have developed or been a part of)

Translation Strategy Webinar - This webinar explains how organisations can get started with their first translation project.

Free Plain Language Email Course - A 10-day course where you'll receive an email every day with an easy-to-implement plain language technique.

With Us and The Better Together Collective, is all about showcasing the value of working with community. It's about recognising the difference possible when we choose to co-develop, coproduce, and involve real people throughout. Can you tell us what (and who) your community review process involves, and how it changes outcomes and lives?

At Sylaba we enable translators to not only be linguists but also act as cultural bridges. We give them a voice and consult with them on the cultural appropriateness of an English text before it gets translated. We then involve interpreters or community representatives to provide feedback on the clarity of the translations prepared by the translators.

By following this process, we can be sure that whatever we translate has been reviewed by members of the community and everybody involved can guarantee that the translations are clear and respectful.

### What are your hopes for the future of translating and for Sylaba?

I hope that more education is provided to organisations so they are better informed and can make better decisions when it comes to translating content. I hope for Sylaba to continue to be a viable business so me and my team can keep influencing the industry.

### Is there anyone that really inspires you in this space?

I have been lucky to meet and learn from great professionals whose values and work align very much with mine. For example, Carolina Valencia-Coleman (CVC Social Justice Consulting) and Budi Sudarto (Ananda Training and Consultancy).

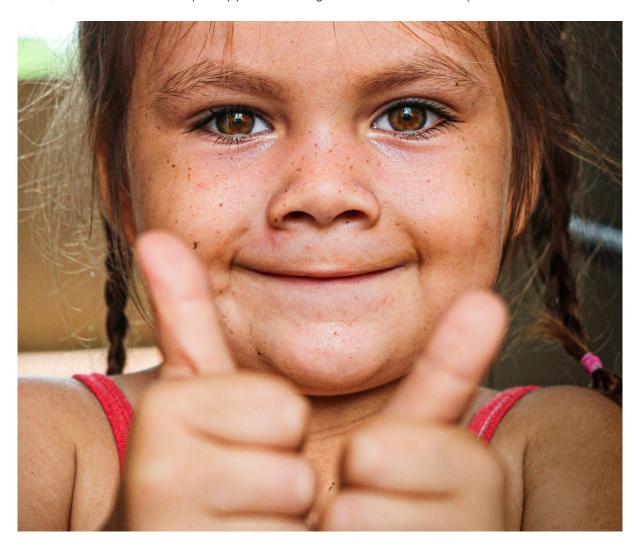
Find out more about Sonia's work, at:



https://sylaba.com.au/

# The With Us Thumbs Up

Tools, resources and contemporary practice that get the *With Us* thumbs up.



### 1. Tackling stigma in the media

When sectors and people come together to tackle stigmatising language.

- The National Communications Charter https://lifeinmind.org.au/the-charter
- StigmaWatch https://www.sane.org/advocacy/stigmawatch
- Mindframe Guidelines https://mindframe.org.au/guidelines

### 2. Building shared understanding

But is it co-design?

Kudos to Kelly Ann McKercher for developing this handy learning tool to help you think about co-design.

Try it out and share it: https://lnkd.in/etTU9nbP



### 3. Listening to people's experiences of co-design and other lived experience led projects – what's it really like?

Take the very first **state of working with** survey + help us paint a picture of what it's really like being part of co-design and other working with projects.

Your input will inform a snapshot of the current state of working with to be shared with all.

Take the survey and share it with your networks, so we know what it's REALLY like as a person or practitioner on the frontline of working with.

Take the survey here:



https://forms.gle/nY8twTjKctWqr9m49





### Thanks for joining us for Issue 2 of with us.

We hope that you found some inspiration and gems to inform your working with adventures.

### Coming up next time

Join us for Issue #3, the 'By People for People' edition. This one will be all about the projects, as we skip the buzzwords and fancy spin and talk to the people on the ground doing **working with** for real.

Subscribe here to be first to know when Issue 3 lands.



Made with love and hope for the future of working with.

Subscribe here

www.bettertogethercollective.com