

## Commons Conversations - El Gibbs & Elly Desmarchelier

Tuesday, Nov 29, 2022. Aired on 3CR Radio in December 2022.

### Elly Desmarchelier

We're talking today about what has to be my absolute favorite topic. And I think it's yours too. I think we're a bit giddy with excitement that we get to spend this time together. We actually get to really deep dive into something we both care about, which is campaigning to create real, tangible change. And you've been campaigning for a very long time in different ways in different aspects. And I want you think about maybe your first campaign you worked on? And what has been the biggest kind of campaigning innovation since that first campaign, what's the biggest change in campaigning that you've seen over your time?

### El Gibbs

Ah, that's really interesting. I think I did a lot of campaigns to make things fairer from when I was a little kid, I've always had a very strong sense of that's not fair and a bit of the oldest child responsibility to fix things. And I have that temperament that it's my responsibility to fix things. But I think the first formal campaigns that I really got involved in, were when I worked in the community sector. So I started working in the community sector from my early 20s. And in a volunteer basis, you know, I worked at a community center for youth homelessness, other places, all sorts of things. The first ones I really were involved with were campaigns around public space, because the 90s, which is well before you were doing campaigns, there was a big campaigns, particularly in New South Wales, by the then Labor government to deal with youth crime gangs. And there was this whole thing about young people are out of control, and young people are wearing their baseball caps backwards. And this is Bob Carr, who was the premier at the time, and he sounded like Queensland now.

### El Gibbs

Well, people have been complaining about young people in public space for thousands of years. But they tried to introduce a bunch of laws around this. And so I did some reporting, because I was training to be journalist at the time and worked with the youth peaks. And so we ran events with young people who were, you know, some of those young people from Western Sydney, talking about what it meant to them, and interviewing politicians and giving them a hard time, which was great fun. And then, for Youth Week, a whole lot of young people camped out in tents behind the New South Wales Parliament House. We had a need to yell at the government about why the laws they were planning to pass, which would have said young people couldn't be in groups of more than three, you were not allowed to wear a cap backwards. A whole lot of this incredibly draconian legislation.

### Elly Desmarchelier

That sounds tighter than like an outlawed bikie gang.

**EI Gibbs**

Exactly. So the legislation was defeated, and the youth protests were reported on, and it was all very exciting. And it was a really great campaign to be part of a to be supporting young people themselves, teenagers taking part in it and holding politicians to account. So I think it really set a kind of template for the way that I've tried to do the campaigns and things that I've been part of ever since. And it certainly gave me an insight into people power. Showing up, protesting, having fun, being innovative in how you do things, but holding politicians to account and saying what you're doing is outrageous. That the people themselves who were affected in this case, it was young people, particularly First Nations young people, young people from refugee and migrant backgrounds, poor young people and young people from Western Sydney, really said to the politicians, 'This is outrageous. You're not going to do this in Mosman, which is a wealthy part of Sydney, you're going to do it in Bankstown'.

**Elly Desmarchelier**

It's so funny that you said the word fun there. Because I'm always talking in campaigns about fun. And everyone's always like, we've got too much to do to think about fun. And I always say to people, 'no one wants to join a team that looks like they hate each other and then they're hating what they're doing'. If you look like you're having fun people want to join in. Fun is such an underrated energy of a campaign, in the hustle and bustle to get stuff done fun gets lost along the way. And it's such a motivating factor for people to join in.

**EI Gibbs**

Absolutely, absolutely. I mean, you don't just you join a campaign because you have a passion, and you can see an injustice in the world. And yes, a lot of that is really serious. But joining together with other people is a great thing to do. And you get to meet other people and work together. And it doesn't all have to be serious. And I think if it is all serious all the time you've missed some of the good stuff, which is forming friendships and relationships that are the core of how we can make change.

**Elly Desmarchelier**

Yeah, absolutely. Now, one thing that I'm constantly thinking about is, how do we make campaigns more accessible because the traditional tactics we use in campaigning like door knocking, letterboxing, phone calling, are really, really inaccessible. But they work, you know, one on one conversations with people work. So I'm always thinking about how can we start to make campaigning more accessible? Is it about breaking down those traditional tactics? Or is it about creating new tactics? What are your thoughts on it?

**EI Gibbs**

I think it's a combination of those plus a third one. I think that disabled people have been using innovative and accessible techniques to do campaigns for a really long time. And I think it's one of the things that I've really focused on because a lot of the time over the last 30 years, I've been stuck at home. And so being stuck at home during COVID for lots of people was like, 'wow, this is terrible'. I'm like, 'Yep, my reality'. This is mostly my life. So a lot of the time, I have done a lot of that kind of activism online and the organizing online.

I've done some very silly things over the years. But one of the things that we did in the 2004 election: There was Billionaires for Bush, there was a campaign for George Bush, it was a satirical campaign where people dressed up as billionaires to demonstrate the connection between money and politics. So we adopted this in Australia called Liars for Howard. I remember being extremely sick at the time, and we did a lot of the organizing via email, because it was the olden days, and email groups and posting on blogs to organize these events, but then we would go and do these snap events in public like standing in Martin Place holding signs saying 'Medicare's a privilege, not a right' and handing out flyers. Of course, we were completely unsuccessful. Howard got control of both houses of parliament.

**Elly Desmarchelier**

I don't think that was because of your campaign though!

**EI Gibbs**

It was one of those ways of trying something new, working mostly online, with flash mob type of things, and then doing the occasional thing in public. I think we only ever did about four or five in person events. And the rest of it was these online personas, where we were just pretending and basically trolling. It was just a large trolling exercise. It was a lot of fun.

**Elly Desmarchelier**

Sounds like how most of our elections are completely done these days. Massive trolling events!

**EI Gibbs**

These were there was a lot of us who were testing out how do you do this online. And for me, I was really excited about it, because it meant I could participate and I didn't just have to sit on the sidelines and be frustrated. I could actually participate as a writer, a person sending emails and doing all of that stuff. I could actually do that. So a lot of the techniques and the tricks and the tools that I've got that I use today are things that I've learned in the early 2000s when I literally was stuck at home for a long period of time. I was in hospital for a long time and then I refused point blank to go back to hospital. There was a degree of support cobbled together to keep me at home. But I was stuck at home, I had 10 hours a week of work that helped with my disability support pension, paid the rent, and to distract myself from what was happening to my body and everything else I just got incredibly obsessed with online campaigning.

**Elly Desmarchelier**

Oh look, I had to retell the story recently of how I became obsessed with American politics. I got incredibly unwell as a 13 or 14 year old in 2007. And I just became obsessed with the US Democratic primary, like obsessed to the point where I knew all the electoral votes in each state, and when they were coming up for Super Tuesday, and I had the map on the hospital wall, and my doctors knew not to interrupt me during PBS news hour, my one hour of joy. I think you're so right, I think it's pretty incredible how quickly people with disability were able to use online tools in the defend our NDIS campaign. You know, we did 10 virtual town halls in five days, and people with disability showed up, but then they also really showed up when it came to attending Melbourne protests in the final week. So we're the hybrid campaigners, aren't we? Oh, 100%.

**El Gibbs**

There are people that I know on Twitter that I first met online 20 years ago, who were part of that original blogging kind of explosion that happened, and where there were many of us talking about being disabled, being queer, you know, wanting change in the world, you know, it was a conservative government. And here and in the US, it was a very difficult time with the war. And it was one of those times where it didn't feel like there was a lot of questions about where does the progressive government come from? Where does the progressive future come from? We kept losing elections. So there was a lot of questioning about tactics and about strategy. And for us as disabled people, how did we get into that game? And how did we actually then start to talk about ourselves? I mean, I wasn't connected with the disability rights movement here. So the people who were organizing around the Disability Discrimination Act, or even before that the Disability Services Act, and then doing all of that preliminary work before the NDIS, I was completely disconnected from that. But I was very involved in other kinds of politics. So when I started working on an election campaign in 2006, everyone just kind of went, where did you come from, out of nowhere with all of these skills and knowledge? As I said, I had been sick for a really long time but they hadn't, it didn't quite click with them. How a disabled person who was suddenly well enough to work on the election campaign?

**Elly Desmarchelier**

That's absolutely the 2022 election for me. Everyone being like, where did you come from? And where do you get these skills from? And I'm like, I'm Elly, and I'm from Queensland, I'm here to help - to steal a line from Kevin Rudd.

It's hard to ask someone about their biggest campaign failure. I don't mean in the sense of like a big campaign loss. I mean, like a tactic that just went really wrong. Just a real stuff up. Can you think of a time when it just fell over? It just didn't work? And you really learned something powerful from that moment?

**El Gibbs**

Oh, look, lots of it. I mean, I think if you are involved in campaigning, you lose most of the time. I really think, you know, like, I've worked on one election campaign, and our person didn't get reelected. You know, we worked really, really hard and we use every tool. But it was a change of government election. It was the 2007 election. It was the landslide. And it didn't work. You know, all of what we did didn't work. I worked on other elections that did work. And so we use pretty much the same tactics. It just was the circumstances at the time.

When it comes to disability: One of the campaign's that I was part of was a campaign for the Royal Commission. The campaign I walked into and I was told that 'this is yours, please continue' had used a lot of kind of passive language. It really highlighted the dreadful experiences that people with disability had and are having right now, that they wanted the Royal Commission to examine. It came after the 2015 Senate inquiry that really lifted the lid and shone the light on the extent of violence and abuse against disabled people. But it wasn't working. People weren't engaging online, people weren't engaging in terms of using the tools, they weren't doing the calls to action or taking action.

So we pivoted the campaign and rejiggered it to a much more powerful and simple message. It was about taking action in the face of this overwhelming tide of violence and for people with disability to demand that they had their voices heard. It was a very different kind of frame on a campaign. It put people with disability not as passive people in it, but as active, saying, 'This is what we need to sort out this problem'. And using the Royal Commission as the single ask was incredibly important, because it meant that every time we thought about violence in any context, the answer was always we need a Royal Commission. Reflecting now, back on that campaign, I think I didn't put enough time or work into what it was the Royal Commission would actually do once we won the Royal Commission, what actually would that mean and how would we hold the Royal Commission to account, how do we use the royal commissions activities, to get change?

### **Elly Desmarchelier**

So literally as you're speaking, I was thinking, it's almost like we need another campaign to get our voices heard. Even though we won the Royal Commission, it feels like our voices aren't heard. And this Royal Commission, most people don't even know it exists. It almost feels like a campaign is needed now. So it's so interesting that you have reflection.

### **El Gibbs**

In the last two years, I now work as a consultant, and I don't work for a particular organization, and I've been able to work with organizations around how do you use the Royal Commission as a tool, and as a tactic to achieve your strategic goal. So if your strategic goal is, changing the situation for First Nations people with disability, how do you use the Royal Commission as a tactic to bring attention to it to argue for change. This year, I've mostly worked with the peak for people with intellectual disability. And we've been able to use the Royal Commission hearings, particularly to leverage the debate around employment and change the debate. And we have been doing that really well. It's been nice to be able to have the opportunity to fix that, to almost fix the thing that I couldn't do beforehand, which was be strategic about using the Royal Commission to create change.

I am very worried about the Royal Commission. I'm worried about the recommendations, we have no idea which direction they're heading in, they've produced no interim reports with recommendations, there has been some very worrying statements by the chair. There's a lot of areas that they have just not looked at all, and a lot of places and a lot of voices that haven't been heard. I'm very concerned with what they're going to actually recommend.

### **Elly Desmarchelier**

I'm very concerned about that as well. My concern is that recommendations will come out which are tinkering at the edges of the status quo rather than the roadmap to structural reform that we actually need to end things like segregation, which underpins most violence, abuse and exploitation. That's because, in large part, I feel like there isn't the public pressure on the Royal Commission to deliver anything of substance.

What role do you think both people with disability but also the organizations that represent them have? What can they be doing over the next year before the Royal Commission releases its recommendations. If you were running the national campaign around the Royal Commission, if you

were put in charge as campaign director, what would your advice be around how we make sure we don't walk away from this Royal Commission with nothing but a handful of like, nice to have but nothing that's going to really revolutionize people with disabilities' lives?

**EI Gibbs**

Look, I think one of the one of the traps that I think we often fall into in disability advocacy is needing to get on with things. It is because the problems and the challenges and the barriers that we face are really big. There are lots of things that are really terribly wrong in the lives of disabled people. And we often try, we say, we have to fix all the things. And I really get that 'I want to fix all the things' but we have to be a bit more strategic. There is a culture in our national organizations where we will work in a way that isn't good for disabled people. And part of that is that we aren't strategic. So being strategic about, we have nine months until the Royal Commission reports. What are the key goals that you want to achieve? And how do you prioritize one or two big things, and start doing the work around getting those reforms?

I think one of the challenges always with a new government is that they work differently. We've had nine years of a coalition government, and we've got a brand new government, they have super keen, very excited ministers, very keen staff, very keen on getting change. And they come to people and say, great, what do you want to do? And then one goes, All right now, laundry list. I think, being very specific about the change, and very specific about the mechanisms for that change, and how much will it cost. If you want to reform, you know, we need all houses to be painted, great. So what color? Who's going to paint them? When is it going to be done by? Who's going to pay for the paint? What kind of paint are you going to use? Being specific, and getting the numbers, doing all of that stuff, and then going and prosecuting your argument. That is not making a goddamn submission. It's actually doing the work around the advocacy piece, the campaigning. I often think people think campaigns have to all be done in public. Some of the best campaigns you would never know about never happen in public, they are all behind the scenes.

**Elly Desmarchelier**

Because they are creative, because they're built on relationships.

**EI Gibbs**

Yeah, you need to build those relationships, you need to have trust, you need to understand. Like when I go and talk to a bureaucrat, someone in government, someone in an agency, that kind of stuff, I need to understand the pressures on them. What they need from me, how specific I need to be, and is publicity helpful? Sometimes it is. You build that into your advocacy plan, you take advantage of key moments, then you'd be relentless. You can't just do a submission and go, but we asked them, and they just didn't do it. It doesn't work like that.

**Elly Desmarchelier**

I once worked on a campaign where the opposition called my candidate relentless. We ended up getting a permanent marker and writing on the whiteboard: Be Relentless. I think that is constant determination to just keep going and keep answering the questions and finding the way around. I think

people think campaigns are just won in a day, but often they have decades of people's blood, sweat and tears that are poured into it. But there's just a flashpoint that happens where it all comes together.

### **El Gibbs**

There's a rule in political communication: tell me three times. Again, this is the olden days before social media, but if someone gets a flyer in the letterbox, answers the door and has conversation, sees a street stall, picks up a newspaper, like a free newspaper that you party hands out at a train station, they might just start to know that there's even an election on. It's devastating for all the people who are slogging over leaflets, how to votes, and on social media ads and all of that stuff. If you are getting sick of hearing your message, other people are just hearing it for the first time. That's right, we often don't understand that in the community sector and I include the disability sector in there, we don't have the skills or understanding around some of those basics about how you do advocacy, and how you do campaigns and how you get change. I know we have had those skills, because I read about the campaigns that, you know, activists ran in Melbourne, where they squatted in terraced houses to raise awareness around them being stuck in institutions, you know, people with intellectual disability creating absolute havoc, so they could get decent housing. Leslie Hall crashing the Melbourne corporate spastic center beauty pageant to hold up a sign because they wouldn't let women with disability participate. Another bunch of women with disabilities secretly bought tickets and got into front row, and then stood up in the middle of it with these signs these are women.

We come from a lineage of these incredible campaigners who just didn't give up. The fact that we live independently, and we have supports, and we do the things that we do is from all of the work that they did. So I often feel like I have a responsibility to them, to people like you to do this work well, and to learn from the people who came before me, so that I can actually pass on the campaign experience that I have, so that we can all get better at doing this campaigning. Often we do it outside of our institutional structures.

### **Elly Desmarchelier**

Oh, absolutely. And can I ask because, you know, I think there are some other groups that have been incredibly good at passing on the stories of the elders that came before them that made history, that made change, that pushed for things. I've never heard that story in my life, and I'm a disability rights campaigner. Do you have any recommendations of where people can read more? Who are the icons of the disability rights movement in Australia? Any suggestions because I think knowing that history and understanding that you come from a line of people, which inherently you do know that someone fought to get you where you are today. But to know those stories in those people's names, is just, it fills your cup. And where did you find all of this out?

### **El Gibbs**

Look, there isn't just one place. A good place to start is Professor Lorna Hallahan who is a disabled person. She has written a really amazing history of disability rights activism in Australia, for the Royal Commission. And so if you have a look on the royal commissions research page, you'll find it there. It's about 130 pages, it's really good. That will give you a really good history with a lot of context. Women With Disabilities Victoria and the Disability Resource Center Victoria have a lot of the Victorian history.

The challenge is that a lot of disabled people die far too young. And a lot of our history gets lost. I was talking with someone yesterday who's written a history of people with intellectual disability in South Australia. Again, only some people's histories get remembered. And I think it is incredibly important that more of disability history gets written down and remembered. I have a bunch of things that I found over the years. Margaret Cooper wrote a fantastic history of women with disabilities in Australia that actually looked at why they did a walk out of a particular international disability conference. People with disability did a walk out of that because they didn't ever get a speaking spot. That led to the start of a lot of our organizations all together 40 years ago. Then because all of the positions were taken by men, all of these women were all stuck there, and there were great stories about what they did in the 80s and early 90s, about trying to work together. So there's a book I've got called Oyster Grit, which is kind of a book of stories of women with disability, you know, from the sort of 40s 50s and 60s and 70s. Lots of our pioneers in Australia are people who are blind and people who are deaf, they had organizations, right back in the 1800s.

Of course, First Nations people had their own inclusion of people with disability that was very different to the colonialist structures. When we talk about our history, we have to remember the damage that was done. The disability that was brought by the invasion and the colonial stealing of culture and of land and the murder of people was just catastrophic. So that is an important part. Dr. Scott Avery's history Culture is Inclusion is really important as well.

Then the polio waves and the world wars were also really important in terms of so many people who survived polio were very disabled, and they were pioneers of the of disability rights movement in Australia. As well as people who came back from the war, that was a lot of the reason we have the DSP and a lot of Commonwealth rehab services, some of those kinds of structures came out of the First World War because so many men came back so disabled. And it was such a shock to people.

### **Elly Desmarchelier**

I have a reading list now. It's gonna be fun. I've cracked it open. I have one final question for you, which is, I want to know what your most maybe controversial piece of campaigning advice that you wish everyone would follow is? The one that people get heated about but you sit there and you argue the point with people every single time, but you stand by it, and you reckon every campaign, particularly every disability campaigner in the country should be doing? What's your hot take that you wish everyone would pick up?

### **El Gibbs**

Rest more. Do less.

### **Elly Desmarchelier**

Oh, my God. That's really the one?

Yeah. Yeah, we need to work out a way of campaigning that suits us, that suits our body, suits our minds, suits our disabilities, suits our everything. We have to make that okay. I think that we have set too much of up of a culture where it's not okay to actually be disabled. And that is bullshit! So, I want us to do the smarter better campaigning, more strategic, and not kill each other, kill ourselves trying to do



it. I just, I watch you, me, all of us work until we absolutely drop and it cannot be the way we do this. So I am determined to try and figure out a way that we as disabled people can make this sustainable for us to get the change that we want. Because right now, what has happened is our organizations are now run by non disabled people. Because this pace means and the way that this systems and structures are set up, there is no room for us in our own organizations. And that sucks. So we have to do better. We have to have a different way of doing this. I'm not interested in martyring myself for the cause. No thanks, I want time for gardening. I want time to do nothing. I want time for knitting, time to hang out with my friends. I don't want to, or it shouldn't be expected that disabled people will campaign at the expense of the rest of their lives whilst we are campaigning. So we have a life and so that the people that we know, who don't have a life, have a life.

The other one is, including all disabled people. Like at the moment, I'm working with just the most fantastic people with intellectual disability, who have a great deal of expertise about change making, about the employment work that we're doing, and about how to do it really well. And I'm learning an awful lot, but they are often left out of how we do stuff. I think we as disabled people can do better about including people. So they're my two big things. I don't know whether that's what you asked me.

### **Elly Desmarchelier**

Honestly, well, when I said hot take and you said rest - actually I got chills and I took a breath. I was just like, I'm so tired. It's actually a really hard thing to admit in our community because there are people working so hard everywhere. You don't want to be the one that's like 'I'm really tired, I can't'. But you know, I was on Q&A last night had five meetings back to back today.

### **EI Gibbs**

I mean, I have an autoimmune disease, I have an autoimmune disease that gave me heart failure six years ago. The fatigue I feel is like thinking through molasses, and if I don't get enough rest, I am rooted. But at the moment, you know, I survive on a great deal of coffee, Diet Coke, and I go to bed at nine o'clock. None of that is visible in a way that I think is unfair. I've had other disabled people say, I could never do what you do, EI. And I think God, what kind of example am I setting? It's terrible. So I think I need to be more honest about the toll this takes on my body, and about how I actually manage these periods of really intense work. Also, I worked recently in this project that we're doing that we don't have enough resources, and we need more people. Because I'm not willing to work 60 hours, I can't, I cannot work 60 hours a week anymore.

### **Elly Desmarchelier**

I'll put my hand up and say during these periods of time, I rely on taking medication, otherwise, I would fall over. But that's unsustainable for long periods of time and taking a break sometimes feels like letting down the team. You're right, that is not the community that we set out to build. Really, it's the hottest take you could have had.

### **EI Gibbs**

Look, I'm influenced by Leah Lakshmi Piepznia-Samarasinha's work. Their book Care Work is just essential reading, to think about how we do this in a way that honors our bodies, that honors the way our brains work, that honors all of it. How do we do that? They've got such heart and soul about how

they talk about working in community. It's one of those things that I think about a lot. We can only do this together. We can't do this by ourselves. So how do we make it so that for all of us, it is sustainable? Because at the moment, it isn't, it depends on so few of us that it isn't sustainable. So we have to do a better job. I still don't know how yet.

It gives me the energy and fills my cup every Friday afternoon chat with you, we do these long chats all the time. I hope that you know that you are a campaigner that I look up to more than anyone else in the disability community, as someone who has created momentous change and does not get the warmth and the congratulations that you deserve for your work. So I'm incredibly proud to call you my friend and my fellow comrade in campaigning.

**EI Gibbs**

100% and I'm very proud of all the work that you're doing and I was cheering you on Q&A last night as you gave it to Robert.

**Elly Desmarchelier**

He had it coming, didn't he?

**EI Gibbs**

But hopefully we can encourage more folks to come into this world as we've got a lot of change to make. Let's do it.

**Elly Desmarchelier**

It is a hell of a lot of fun. Some of these Friday afternoon chats are just hysterical laughter because it's ridiculous. So yes, we talk about it being hard, but it's a fun fun way to live a life sometimes.

**EI Gibbs**

Sure is my friend.