**Thinking Outside the (Tick)box Conference - Speaker notes**

In this document you’ll find the notes from the speakers at the Shaping Our Lives conference on 1st November 2022. The notes and slides from the presentation by Deirdre Maguire from Zebra Access are contained in a separate Powerpoint and PDF documents. All these notes are available on our website.

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## Peter Beresford, Co-Chair of Shaping Our Lives

Peter is the co-chair of Shaping Our Lives. He opened our conference with a plenary launching our statement on social care, reflecting on the history of our movement and on the importance of intersectionality.

**Notes**

Hello everyone, it’s great to be here. It’s good to see everyone.

The first thing I want to do today is to officially launch the Shaping Our Lives Statement [Rethinking social care – fixing our broken health and care system](https://shapingourlives.org.uk/report/rethinking-social-care/). Social care here is in long-term crisis. Working together we have developed this long-term strategy for ensuring there is a system which is person centred, participatory, supports the sustainability of the planet and makes it possible for every disabled person and service user to live their lives on equal terms as non-disabled people. We will fight to achieve this alongside other disabled people’s and service users organisations committed to achieving the same rights, entitlements and disability equality.

What I want to talk about today is what is really the focus of today. It’s about each of us being able to value who we are and other people too. It’s about challenging all the history, all the past, where too often it was about putting people down, devaluing and putting down particular groups. Making us fear and dislike other people, each other, even ourselves because we’d been encouraged to believe there were things wrong with us, or not good enough about us.

Sadly, these things aren’t just in the past. For many if not all of us, they can be part of our present, our lives, what we have to deal with on a daily basis and what can intrude in and even spoil our futures. I’m talking of prejudice and discrimination; of people being treated badly because they are seen as part of a group it’s ok to put down, treat badly, even hate and commit crime against.

Shaping Our Lives today we are celebrating our anniversary. We are proud we are still here to be a voice of disabled people, of service users, speaking and acting for ourselves. We know we have things in common, the oppression, discrimination we face, for example. But we also know that we are all different. Shaping Our lives got together to challenge the barriers and exclusion, the discrimination and oppression disabled people and service users face. But we have always also been committed to challenging other discriminations people face, on the basis of racism, sexism, homophobia, classism, ageism, mentalism, transphobia, and so on.

And that’s where this issue, this word I want to focus on especially today comes into it. The word is intersectionality. Yes, it does sound like a jargon word. I often find it difficult to remember and then I think “what do we say when we come to a cross road, where traffic crosses - we call it an intersection” and then I’ve got there -intersectionality. Yes, it is a big word, but I do think unlike a lot of them it is a really helpful one. Let me explain why and why it’s important.

Who each of us is, is complicated. We can be lots of things at the same time; a son or a daughter, a partner, a parent, a tenant, a worker, a volunteer, a city or a country person and so on. None of us is one single thing. But sometimes we get seen as one thing, as a disabled person, a mental health service user, as Black, neurodiverse, as older. Often, we get seen as that one thing, that one identity when other people don’t think much of it, don’t value us as a disabled person or a young person who has lived in care.

But the point about this idea of intersectionality, is that none of us is just one thing. And being more than one thing isn’t just a game of numbers like you are a trans person and additionally you are black and a parent. Who any of us is, isn’t a layer cake. All the aspects of who we are, our identities intersect with each other. All of them have an effect and impact on the others. Who we are is the complex result of all the elements that go to make us up. So, for me I come from a one-parent family, I am a man, not an identity in some ways I have ever felt comfortable with, a member of a minority ethnic group – a Jew –a long-term user/survivor of mental health services and now an older person. All affect each other for me, all have an influence on how I see other people and the world and on how they see me. It has taken me a long time and a lot of thinking and talking with others to make sense of who I am. I guess it is the same for all of us. It’s great when we have the chance to work through these things – especially with other people we can relate to and who may have similar aspects to their identity. That for me has been the upside of years of distress and using mental health services, all the people with similar experiences I’ve met on the way who have truly helped me come to terms with being me and doing the best I can with it. I guess that goes for lots of us.

But there’s one last point here. Our identities I’m trying to say are complex and may have many different aspects, but we may be associated most with one aspect of our identity, as a Black person, someone who identifies as gender fluid, as a cis woman, that is someone who is seen or sees themselves as having been born a woman. And it may be that identity seems to shape everything because of the responses we get, the prejudice and hate we may receive. And so we connect in particular ways with that identity. We may connect with others around it, we may join groups that centre on it, it’s how people first and still get involved with Shaping Our Lives as disabled people and service users.

And mostly we take such action because we want to challenge that prejudice we experience. We want to be treated equally and inclusively like other people. There is an irony there, we get together separately in order to be treated with the same value and equality as others. But this is because doing things with people like us tends to be the most effective way of achieving change.

And then we also begin to realise that there are still differences among us as I have said, on lines of gender, ethnicity, sexuality, age and so on – and in our grouping those still need to be struggled over if equality in relation to them is to be gained. As I said Shaping Our Lives has always sought to address discrimination along these lines as well as that faced on the basis of disablism and mentalism. We’ve also seen this in work Shaping Our Lives has done in relation to Gypsies, Roma and Travellers and domestic violence, where we have learned more about the additional discrimination and barriers that disabled people with multiple identities can face in relation to both those experiences and situations.

The people and groups who have developed struggles on the lines of their identities and the experiences they have had in their lives of exclusion, hate and discrimination in relation to gender, ethnicity, sexuality and so on have come to be seen as New Social Movements. New Social movements in my view, the Women’s movement, Black civil rights movement, movement for LGBTQ+ and so on in my view are central in struggles for equality, social justice, peace and the future of the planet.

But there is also a tendency to hierarchise difference and diversity, i.e. to suggest or think that some kinds of difference are more important than others. This is generally unhelpful, because being oppressed is equally tough for whatever reason you experience it. Also, what we know from intersectionality is that it doesn’t really make sense. It isn’t better or worse to be Black, a woman, gay etc. etc, because we may be any of those, any combination. That is another of the values of intersectionality to remind us of this.

And the intersections of our identity, the various overlaps there may be – are important as a reminder in another way, they remind us of our common shared struggles against hostility, hate and discrimination. And that I think is one of the most important things for the future. I think people who are powerful now and shape our lives in damaging ways are very keen to divide us – as Black and white, disabled and non-disabled, citizens and asylum seekers, people on benefits and not. So I believe that intersectionality by reminding us of our commonalities of oppression and our many overlaps helps this nasty pressure to be divided. And I think that this will be important for the future in challenging the cruel divisive politics we now have. It is a message for all of us including Shaping Our Lives to highlight our overlaps and common experiences as well as our difference and uniqueness because all of us together are much more powerful than the rich and powerful few who divide us and take over from us. We will shape our lives by building alliances between our different movements, our different identities and experience. That’s the way to go for a better future. And I think this conference is part of this great new journey, helping bring us all together, see what we have in common not to be manipulated to see difference as divisive and something to fear. We’re here to build on that, celebrate it, and work together to give even more power to it.

## Charlie

Charlie talked about the process of transitioning gender medically and legally in the UK, and highlighted how Disabled trans people are disproportionately impacted by the barriers built into this process, as well as reflecting on his own experiences of being autistic and trans. He also reflected on the common ground shared by trans and Disabled people, as well as calling for greater solidarity and mutual understanding.

**Notes**

I’ve been invited to talk about my experiences as a Disabled trans person, and I thought I would focus specifically on how navigating the current process of medical transition within the UK is complicated by being Disabled. Before I start, though, I want to flag up that when I say trans people, I include non-binary people in that – there is a common misconception that non-binary people don’t pursue medical interventions, which isn’t true. I also want to acknowledge that not all trans people seek medical interventions for a variety of reasons, which include the impact of physical disabilities and long-term health conditions. A model which requires trans people to undergo medical intervention innately excludes disabled people.

There’s two reasons why I wanted to focus on this aspect of transition. Firstly, although trans people are increasingly discussed within the UK, most cis people have little knowledge or understanding about the process many of us navigate. Secondly, I think that there are some strong parallels with the experiences of Disabled people in accessing services and support.

In a nutshell, to access medical transition through the NHS at present, your GP needs to refer you to a Gender Identity Clinic for the diagnosis process. You will then have to have two assessment appointments before receiving hormones; further assessment appointments are required for surgery, which you need a diagnosis for. Private services are available which often enable a much quicker, more straightforward route to medical interventions – waiting lists are shorter and they require fewer assessment appointments, but Disabled people are less likely to be able to afford this.

I’ll use my experience as an example of how the NHS route bears out in practice. I socially transitioned to male in 2017 aged 26, meaning I told friends and family and began using he/him pronouns, and got a referral from my GP to attend the GIC. My first appointment was a year later, in March 2018, and I started hormones in February 2019 after my second appointment; by summer 2020, at my third appointment, I had received both signatures to approve me for chest masculinisation surgery, also known as top surgery. On my 30th birthday at the end of 2020, I was still waiting for an assessment with my surgeon. I’d been living as a man for nearly four years by this point, and one of the most difficult things about it at this point was my chest – while I was happy with the effects testosterone was having on my appearance, it created a bigger disconnect with my body. When I was first referred in 2017, I was keenly aware that the waiting times had become a great deal longer and I felt really stressed about it. It will now take you over four years to have your first appointment with the Gender Identity Clinic in London; this is a standard length across the country.

Something that often comes up in discussions around transition is the sense that it’s important for trans people to wait a long time to “make sure”. Many trans people have shared that by the point they’ve decided to transition, they have been considering it for years already. I’d agree with that. This was also compounded for me by being autistic. Autistic people often experience alexithymia, which is a difficulty around identifying your feelings, and this made it hard for me to realise I wanted to transition. From my teens onwards, every few months I would re-read the Wikipedia page for gender dysphoria, and I wouldn’t make the connection with what I was feeling, and I’d go back to thinking transition wasn’t necessary.

I also had a lot of internalised ableism about being autistic – I felt like I could never trust my sense of self, and that I’d never be capable of making informed decisions. This was even before the current claims of concern around autistic people transitioning – I can’t begin to imagine the difficulty I would have faced if I was transitioning now.

It took me until after being on testosterone and having surgery to realise that I’d had a very classic case of dysphoria the whole time. As a result of being able to transition, I’ve had the mental space to overcome the most intense parts of my life-long mental ill-health, which has meant I can be more independent from my family, have meaningful relationships with my loved ones, and live a more fulfilling life generally. I’m enormously glad I managed to get to the point where I could realise this was what I needed to do.

Although it was a difficult process enough coming to the point at which I was ready to confront the possibility of transition, as part of the actual process I had to then field intrusive questions about my personal life which felt designed to trick me. I was warned about this, and I was mentally prepared for it, and at the time I really minimised how difficult I found it because I had to just get on with it. But it was a struggle, and if something traumatic comes up during those appointments you have to rely on having a good support network, because there isn’t really anything in the way of provided care.

This is a common experience, and it’s also common that trans people generally don’t feel able to report clinicians who have overstepped the mark for fear of repercussions or further delays. According to the [Trans Lives Survey 2021 conducted by TransActual](https://www.transactual.org.uk/trans-lives-21), 85% of non-disabled trans people report delays in transition healthcare – this jumps up to 93% of disabled trans people. From experiences I have observed my peers going through, reasons for this include a reluctance to provide healthcare to people with experience of mental ill-health, requirements to be below a particular BMI, and lack of knowledge about physical disabilities from clinicians.

As I’m sure you’ve realised, this all takes an enormous amount of time and mental energy to manage. I haven’t touched upon the non-medical aspects of transition, such as changing your name and details across organisations, widespread transphobia, or getting a Gender Recognition Certificate, which also require time and energy. It has often been remarked that being Disabled is a job in and of itself – this is amplified for trans Disabled people. The level of expertise that both Disabled and trans people need to have about their healthcare needs also contributes to an increased amount of labour in practice.

And even without the large number of people who are members of both communities, even without practical similarities, the fight for Disabled and trans rights are innately linked by shared philosophies. We’re all fighting for autonomy and agency, for dignity and respect, and against completely avoidable misery. When either community are attacked, whether by state or society, it sets precedent for how the other will be treated. We are currently living in a political and social context where all marginalised people are increasingly vulnerable. Recognising how deeply interwoven our experiences are is an important basis from which to build a resilient movement for social change – and this is why a diverse, intersectional inclusive involvement movement matters.

## Deenah Al-Aqsa from Hidayah LGBT

Deenah is a Programmes Officer for [Hidayah LGBT](https://hidayahlgbt.com/), a charity dedicated to LGBT Muslims. She is also a journalist with bylines in the Metro, Lacuna Magazine and PinkNews (portfolio of articles [here](https://www.clippings.me/deenahalaqsa)). Deenah writes about her experience as a queer Muslim woman and her talk focused on the importance of intersectionality as it relates to the Equality Act’s protected characteristics, as well as her own experiences.

**Notes**

Disability as defined in Equality Act

You're [disabled under the Equality Act 2010](https://www.gov.uk/definition-of-disability-under-equality-act-2010) if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

I still don’t know if my disability “counts” despite meeting this definition because like others have mentioned, there are certain perceptions of what people consider to be disabled. I have several mental health diagnoses including Borderline Personality Disorder and Obsessive Compulsive Disorder as well as depression and anxiety that I’ve been taking medication for over a decade. And having faced racism and Islamophobia from a young age (starting from five years old) until present day, as well as homophobia and heteronormativity since being a teenager, I feel like I am constantly in a “fight or flight” state. I’m always on edge, always paranoid - as [someone who is closeted](https://metro.co.uk/2022/06/06/i-wont-ever-be-able-to-come-out-ive-made-peace-with-that-16741855/) - [about being outed by the work I do](https://www.wearequeeraf.com/being-a-closeted-queer-muslim-journalist-is-like-being-a-superhero-secret-identity-and-all/).

Overlaps with queer experiences and disabled experiences

* **“Coming out” -** I kind of had to “come out” as disabled to my family who did not take it well and that’s why I’m not out to my family as a lesbian.
* **Terminology** - we often have a lot of big disagreements within our own communities about the use of certain words, like “queer” versus “LGBT” versus “LGBTQIA+”, and “people with disabilities” versus “disabled people”. I definitely think these discussions have to happen, but I don’t think that we’ve solved ableism simply by changing language. On its own, that is a start, rather than an end, to a bigger conversation about inclusion.
* **Visibility**
  + What “counts” as being queer? (thinking about typical stereotypes about LGBTQ people - when many people think of lesbians, do they think of a brown woman in a hijab or a butch white woman with short hair?)
  + What “counts” as being disabled? (see above re my own struggles with even claiming the label because what usually comes to mind when people think of disabilities are the more visible or apparent kind - wheelchairs or hearing aids, rather than the kind that are invisible and often even less understood than the visible disabilities)
* **Conversion practices (or similar)** The tendency for religious and cultural groups to try and “cure” you of your queerness or disability despite it being an inherent part of your identity (Hidayah has co-signed this [open letter](https://twitter.com/BanCTorg/status/1595041248389304320) to Women & Equalities Minister Kemi Badenoch and this [open letter](https://un-aligned.org/un-in-focus/letter-ohchr-ban-conversion-therapy/) to the United Nations Human Rights High Commissioner about the need for banning conversion therapy)
* **Intersectionality** 
  + Considering how certain voices even within a minority might be louder than others
  + That means certain groups can be neglected or not prioritised as much (i.e. Black disabled people, Black LGBTQ Muslims, disabled LGBTQ Muslims, nonbinary and trans Muslims, etc.)
* **Checking your privilege as an activist** 
  + There’s a lot of virulent anti-Blackness in Muslim communities
  + Part of what needs to be done is around acknowledging your privilege in your activism
  + This includes me as a cis woman,
  + Among queer Muslims there are the “default” queer Muslims (South Asian, Sunni, cis gay men) and while I don’t tick all those boxes, I do tick some
* Hidayah is an organisation for queer Muslims but it’s also important for us to acknowledge the gaps in our activism and the work still needing to be done re accessibility and inclusion
* The most important overlap is the importance of community and shared experience and peer support, and ensuring that we make these accessible for everyone - whether it’s Pride, meetups, online events (like Book Club)

## Dominic Watters

In a pre-recorded talk he discussed the contempt he has experienced when raising awareness of food insecurity and fuel poverty in professional social work spaces. Dominic’s talk was a pre-recording and below is the transcript.

You can find Dominic on Twitter at [@SingleDadSW](https://twitter.com/SingleDadSW?s=20&t=_cOYpRxhFYRWehK4ZSf3Qg).

**Transcript**

Thank you for the opportunity to be here and to be able to share some of the obstacles I faced in trying to make social work organisations have a deeper understanding of poverty.

My name is Dominic Watters, some people may know me on Twitter as [@SingleDadSW](https://twitter.com/SingleDadSW?s=20&t=_cOYpRxhFYRWehK4ZSf3Qg). I guess to just briefly introduce myself professionally: I am a newly qualified social worker, working with children in care. I am an author. I have a book out, [which is on Amazon](https://www.amazon.co.uk/Social-Distance-Work-COVID-Capsule/dp/B096TQ6YCL/ref=sr_1_1?crid=2HYAKTRMO923O&keywords=Dominic+watters&qid=1670268770&sprefix=dominic+%2Caps%2C584&sr=8-1). I am a speaker and I'm delivering training to try and raise awareness and understanding that I've touched upon. I'm also an ambassador for the Food Foundation and I am on the editorial board of the British Journal of Social Workers.

But in terms of like, personally, I am a single dad. I live in one of the most deprived blocks of my council estate and I've survived off Universal Credit, Child benefit, free school meal vouchers for my amazing daughter and we've always had pay-as-you-go gas and electric meters. And yeah, I'm still on benefits because I haven't yet been paid. I've just started my new job so I am hopefully in that transition, trying to get to a place of less financial insecurity but I say all this because at the beginning of my time in training, I was working with children in care and I noticed how they had a lack of access to nutrition and they were surviving off donations from supermarkets and trips to the food bank for their nutrition. And as a student social worker, I'd often facilitate these trips to the food bank. And at the same time, I was on benefits so this, the beginning of 2020, still on benefits, studying as a single parent, and I was to do with Universal Credit saying I had rent arrears, I was getting notices seeking possession of mine and my daughter's council flat, so we were facing poverty, facing homelessness, living in poverty and there were times when my daughter could eat and I'd have her leftovers or nothing at all. And so, the lack of nutrition that the children in care were experiencing was something that resonated with me and I did research into it, and I came across the concept of food insecurity.

And at this time, which it may seem like how is this possible, food insecurity, there was no work being done. It wasn't being spoken about. And there was no work being done in this country, especially in terms of social work and food insecurity. There was some, there was work being done through my research I noted in Canada, in America, on this inequality. This didn't sit right with me and I saw how the delivery from Greggs bakery on a Thursday to the young people in care, how the staff at the residency would use this as a behaviour control mechanism, where if the young people hadn't obeyed the rule of the scheme that week, they wouldn't be allowed any of that Greggs. And in that sense, I saw how food also can be a vessel for power and control. I've written and I continue to write on this. So please check out my work if you'd like. I've got blogs on the Food Foundation website and a book out.

So why I share this is because, it didn't feel right that, even though poverty is noted in social work as being a vital area of focus and is given a nod to in our professional guidance and frameworks, there is no mention of the actual daily realities of poverty being food and fuel insecurity. So, in the estate I speak to you from now, the shop, it only sells the lowest quality of food produce and you can't top up your gas and electrics so where I live is both a food and a fuel desert in the garden of England.

I'll move forward to kind of talk about the obstacles that threw me trying to raise awareness with professional social work organisations. How the amount of snobbery and contempt that my voice and my presence has had to experience. I've been given opportunities to speak on some platforms but at the same time, I was trying to give vital insights into poverty and the daily realities of actually living in poverty. This was often met with, the best way I describe it, what I experience is, snobbery. "We will listen to but you know, you're not really meant to be in this space and in these professional meetings." Through my endeavours, I tried to create a branch and I tried to have that as the umbrella or platform that I could discuss these issues and the gaps in policy that I located and I wasn't supported in this whatsoever by the social work profession. In fact, quite the opposite.

It really left me not knowing which way to turn, which, when you're also facing court summons for council tax, eviction notices, Universal Credit saying that they overpaid you and they're seeking you to remedy that and you literally don't know which way to turn on top of trying to let people know that people up and down the country, often single parents in council estates are struggling and this is during covid and the cost-of-living crisis. The lack of support I received was really hard to stomach so I ended up creating my own campaign and concept, which is "Food is Care", which is because of those obstacles I faced and that lack of recognition and acknowledgement I really needed and felt it was warranted to have a campaign that located food insecurity directly in the domain of social work.

I should expand a little bit: So some of the responses from leaders in the field, people with influence and high up in these professional organisations was that, when I'd raise these concerns, it was meant with "oh no, food insecurity, that's an issue for public health, that's not part of social work's remit", "oh no, that's for social policy, that's a social policy concern, not a social work concern". I don't think they'd say that today, which is thankful. You know, it's only a year on but the fact this is in the headlines now, perhaps they reconsidered these positions. But that shows this disconnect between the people that have this influence and policymakers to the people living the daily realities of inequality and poverty. So yeah "Food is Care", please support it but at this time, I also put together a book to try and make a voice like mine be heard in a professional space. I reached out to some leading academics and some practitioners and they all contributed, or some of them, many didn't. But some contributed who believed in the work I was doing, contributed short articles for my book and it's a real collection of notes from the covid crisis, my first book and it's called "[Social Distance in Social Work](https://www.amazon.co.uk/Social-Distance-Work-COVID-Capsule/dp/B096TQ6YCL/ref=sr_1_1?crid=2HYAKTRMO923O&keywords=Dominic+watters&qid=1670268770&sprefix=dominic+%2Caps%2C584&sr=8-1)", which is my referring to that gap, that distance, that leaders in the field enjoy from that reality of poverty.

I'm doing lots of work with the food is care campaign, it's got five objectives for this year. We're trying to have food insecurity included in all the professional guidance for social work. Through the work I've been doing I've managed to deliver presentations to Social Work England, the British Association of Social Work and the Department for Education. Lots of work, more to be done but I will end with this because I know it's time-sensitive. There's this concept and I was really thankful I was getting asked to write for my little bit of Twitter action, I was getting asked to write for social work blogs and speak at different events and I was being asked to speak about my lived experience of council estates or my lived experience of poverty or my lived experience of food insecurity. And I was so grateful for these opportunities and I've been writing the pieces and the blogs and I'd be thinking "but this isn't my lived experience, this is my *living* experience" and that is a concept that I've created and is in the introduction to my book.

So, living experience is a development from lived experience. And it's to highlight that these inequalities and discriminations aren't in the past, people are tackling them right now. And there needs to be an urgency, represent the tensions there are with these inequalities. So that's the offering that I've given: living experience. And I've redefined food insecurity as the living experience of food poverty. I will leave it there, thank you so much for having me. Please check me out. If you want to know any more you can [contact me on Twitter](https://twitter.com/SingleDadSW), DM me and I wish you all the best with all the work you guys are doing. Peace.

## Sheldon from the Showmen’s Mental Health Awareness Charity

Sheldon is the founder of the Showmen’s Mental Health Awareness Charity, the Education Liaison Officer for the Lancashire section of the Showmen’s guild of Great Britain. Sheldon is currently undertaking his PhD at Liverpool John Moores University, with the aim to build the first large-scale mental health statistics for the Showmen community.

**Notes**

What it a showman? Who show person? Who are show folk?

A colloquial term for a man, woman, non-binary individual who lives and works in the fairground community. We have a rich historical culture, dialects, a real pot of social classes, artists, Gypsys, Roma, circus folk, market traders, all formed around the 18th century and the materialisation of the showmen community.

We are part of a group of travelling communities – GTRSB - Gypsy Traveller Roma Showman Boater – (people who live on barges.) This acronym is more encompassing of travelling communities which you might have known under the umbrella of GRT.

Within showmen there are also subgroups. Like myself I grew up in a caravan I travelled from fair to fair across the country, but there are settled showmen, or those who operate on the seaside. With coming from a travelling community its typical to often be subject to discrimination. And what I call the fear of the other. They often face discrimination and abuse. Coming from a travelling community there are lots of things that we experience and lots of stigmas as well surrounding mental health.

Coupled with discrimination and stigmatisation, it’s often stigmatised in the community itself to suffer from your mental health. It affects your chance of finding a partner, get business, be accepted in different ways. And members of the GRT are 5-6 more times likely to die by suicide. But only 5 out of 79 suicide prevention plans in the country mention GRT.

During the pandemic I had anxiety and depression and we lost some showmen and some friends to suicide. One evening around the 22nd Jan 2021 I gave 7 of my friends a phone call and talked about founding this charity. I created a Facebook page and a Twitter. The aim is to break the stigma surrounding mental health and we can provide services and developing outreach projects and educational tools.

We have two mental health nurses – child and adult. We have been able over the past 18 months do over 80 referrals. We also do formal diagnosis for showmen to get private diagnosis of ADHD autism anxiety and the list goes on. We’ve been able to do 16 private diagnoses. We took multiple crisis calls of people wanting to come and speak to showmen when they feel suicidal.

We would love to work with more communities. We would love to work with more organisations. We want to be as inclusive and active as we possible can.

Show head, show heart, and show smart.

**About the charity:**

We are a charity founded and run by people from the Showmen and Fairground community. Our aim is to break the stigma around mental health in our community. This includes providing support, information and mental health services to all Showmen in the UK and Ireland, (of all ages).

**Mental Health Services**

The Showmen’s Mental Health Awareness Charity offer funding for private therapy and counselling. The charity has two mental health nurses specialising in both adults & children, who take self-referrals from our website and can assess your current concerns. Once our nurses have completed your screening, they will then source the most suitable therapist or counsellor to support your mental health. If you have found yourself on a waiting list, please get in touch as we may be able to speed up this process for you. We can also help with funding for private psychiatric assessments including (but not limited to) OCD and ADHD. The charity will provide you with 3 months of funding (12 sessions) for therapy services that can be extended depending on circumstances and progress to 20 sessions.  We can also supply a small grant for drugs and rehabilitation services.

**Education**

The Showmen’s Mental Heath Awareness Charity believe that education is prevention. The Charity aims to support our community with educational materials, workshops and lectures for both adults and children. These include our monthly Mental Health Workshops that cover a variety of topics including: Men’s Mental Health, Women’s Mental Health, Suicide Prevention, Mental Health in the Fairground Industry. Furthermore, the Show Smart Campaign celebrates knowledge passed down from generations of showmen.

**Awareness**

The Showmen’s Mental Health Awareness Charity aims to spread awareness through a variety of outreach events and online campaigns to break the stigma surrounding mental health within our community.

Find out more: [Showmen's Mental Health Awareness – Charity Website (showmensmentalhealth.com)](https://www.showmensmentalhealth.com/)

## Sarah O’Brien, autistic writer and engagement professional

Sarah has experience of taking part in involvement and co-leading involvement across charities, research, policy and healthcare. She is currently undertaking a PhD based in King’s College London, exploring Shaping Our Lives’ Inclusive Involvement Movement. Exploring how inclusive involvement and co-production make a difference for autistic people, a case for continued change in healthcare, social care, research and policy. Combining lived experience and learnt experience, Sarah explored where we’ve come from, why change isn’t happening and why it must go further.

**Notes**

I’m never very good at introductions mainly because I will always miss something out no matter how much I think I remember about myself. I’m Sarah, I’ve been an involved person, a person that has involved others and I’m currently researching how we involve Disabled people and service users in decision making.

For me that means a career of trying to look at all sides of what’s happening and blending personal and professional experiences in healthcare, education, policy, campaigns and research. Today I’ll be zooming in on what involvement means for autistic people, what these landscapes looked like before involvement, how the root started to bed down into different sectors, what has started to grow since and where there is still left to grow.

Research is potentially one of the clearest examples of this. For autism research has typically been led by non-autistic researchers and focusing on pathologisation, cures or bio marker pathways. Autism is relatively new to science, formal knowledge about us has existed for less than 100 years, it’s only within the last 15 years that researchers have realized we might have some of our own questions we want answers to.

We’re not interested in autistic mice models of genetics, we want to make our lives better now and for the future. We want a say in those questions, methods and analyses. That’s not something revolutionary in this room but it is and continues to be something that rocks the research boat for those most comfortable with traditional research and power relationships. Things are much better now, involvement, co production and researching community generated priorities are becoming the norm, at least in many universities across the UK and abroad.

Within healthcare, an area of life that should have greater levels of involvement than many of us end up experiencing, autism has also been slow for those in power to catch onto. Without going into details and statistics, autistic people face worse health outcomes, worse health inequalities, shorter life expectancy and higher interaction with health services than many want to grapple with.

Autistic people have and continue to experience institutionalization, abuse in services, poor treatment and staff who do not understand our access needs which often boil down to basic decency. This began to shift when the NHS made autism one of the key priorities of the [Long Term Plan](https://www.england.nhs.uk/long-term-plan/), with autism priorities generated through community involvement workshops. Four years on from that involvement exercise there are small shifts on national and local scales but we aren’t quite there yet. You’re more likely to hear about autism in a panorama documentary or an abuse scandal news story than you will for positive reasons.

The same can’t be said for social care unfortunately. Names like Winterboune View are a stain on social care that exposed the holes in a social care system that does not focus on enabling disabled people to thrive in life. The transition from lessons learnt to actual change has been and continues to be slow within social care. Action is often prompted by highlighting the misery that others have experienced but there are those leading meaningful change with service users of social care from a place of positivity to a place of even better.

Within policy autistic people were housed within the Mental Health Act, a place we never should have been. Changes to provide ring-fenced support and services for autistic people came in the Autism Act 2009 which embedded some community needs. The real change, which still isn’t quite enough, came in the form of the refreshed Autism Act which missed its decade anniversary due to some instability in government and ministers. Involvement was at all levels of the refresh and we saw some positive change but still an over representation of disability charities. Government was starting to listen but radical change isn’t something this government will facilitate, in involvement or policy concerning autistic people.

That’s where we’re at, arguably we’ve moved from bad to better but there is so much further to go. Like all areas of life there are pockets of good practice but pockets aren’t quite enough to change what has been a system built up over lifetimes to finally benefit disabled people.

Involvement needs to be done well, it needs to be meaningful, it needs to tackle power structures and it must be inclusive of the needs of all who want to ger involved.

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## Sukhjeen Kaur, Chronically Brown

Sukhjeen is the founder and director of Chronically Brown, a non-profit organisation working towards tackling the stigma of disability within the South Asian community. In her talk, Sukhjeen gave her personal account of being diagnosed with multiple disabilities that led to her work through ‘Chronically Brown’. She also focused on the intersection of race and disability and the importance of hearing about diverse voices from multiple identities.

We do not have direct notes from Sukhjeen’s talk. However, please find below [this blog which she wrote for us](https://shapingourlives.org.uk/2022/07/29/why-health-inequalities-need-to-be-addressed-for-the-specific-community/) covering the same themes:

Within healthcare, we have all been impacted by the ‘one size fits all’ approach implemented by the National Health Services. We understand and are aware that individuals are individual which need to be treated as such. More recently, ‘health inequalities’ have become a hot topic and with good reason. Ethnic minorities are more likely to suffer with the care provided for their health. Likewise, issues that affect this group such as wage gaps, systemic discrimination and cultural insensitivity have come to the forefront and highlighted the issues we face daily. Even recently we have seen the effects of COVID cases increasing in deprived and ethnic areas of the UK. However, an issue has been occurring within the recent work of health inequalities that is yet to be addressed.

Ethnic minorities refer to a wide range of people including those from Black and Asian backgrounds. However, with close evaluation these terms are broad and do not encapsulate the range of communities within them. For example, the continent Asia includes the subcontinents of Central Asia, East Asia, East-South Asia, South Asia, and the Western Asia. Each subcontinent has a range of cultures, religions, and races within the regions. Therefore, addressing health issues for all Asian backgrounds will neglect the specific Asian communities that are dealing with different health inequalities. Likewise, addressing health issues within the ’BAME’ cohort is ignoring the wider issue and neglecting possible ways to improve health outcomes. Within South Asian communities, we are aware that conditions such as Type 2 diabetes and cardiovascular disease are prevalent. Within African or African Caribbean communities, conditions such as hypertension, sickle cell disease and prostate cancer are most common. By discussing all these health conditions and addressing all ethnic minorities together will let the people that require help fall through the cracks. After all, we are all individual and deserve healthcare that caters to that individuality.

Therefore, I created ‘Chronically Brown’. We empower and educate about disability specifically to the South Asian community. Alongside aiming to shatter the ‘BAME’ title that often refers to all ethnic minorities, we also aim to tackle the cultural viewpoints within the community. South Asian culture has often been the victim of ‘What will people say?’ mentality and therefore left most South Asians with an inadequate outlook. Shaming of disabilities has caused health issues and impairments to worsen. Whether it is the rise of ill mental health in South Asian communities or on-set of type 2 diabetes, the community has failed to reach out for help when needed. Knowing this, the project I am most proud of, from Chronically Brown, is the #desiabled campaign, which encapsulates disability and the South Asian identity together. This has been the start of previously stigmatised conversations around health and disability in South Asian culture. It has also been an outlet for those empowered by seeing more representation of themselves. A branch from our ‘desiabled’ campaign has been our community groups, where we hold a culturally sensitive space for disabled South Asians to talk about anything on their minds. These allow opportunity to break stigma around these conversations by normalising the highs and lows surrounding disability.

We hope Chronically Brown can become a worldwide movement for disabled South Asians as well as pave the way for how ethnic minorities should be treated in healthcare, research, and social settings. Remember our individuality is what makes us human.

Find out more about [Chronically Brown](https://chronicallybrown.com/)

**Deirdre, Zebra Access**

Deirdre is the Community Development Officer for Zebra Access, a Deaf-led charity based in the Black Country. Deirdre delivered a presentation on the barriers that Deaf, Hard of Hearing and Deafblind service users face daily. Notes from her presentations are contained in a separate Powerpoint and PDF documents, which can be [downloaded from our website](https://shapingourlives.org.uk/report/thinking-outside-the-tickbox-outputs/).