



**AT2030**



Global  
Disability  
Innovation  
Hub

## Transcript

### **Disability Innovation Live; COVID-19 & Disability**

Thursday 16<sup>th</sup> July 2020

\*Note – some of the housekeeping and webinar format information has been removed. Small edits have been made to maximise the quality and flow of the transcript. Full transcripts are available on request.

#### **Introduction – Speaker 1: Louise Gebbett**

Welcome everybody, thank you for joining Disability Innovation Live. For those of you that joined our previous Disability Innovation Live, this is the second of our sessions, and today's topic will be focused on Disability, Stigma and the role of Innovation.

Disability Innovation Live is an opportunity for us to share knowledge and experiences in disability innovation. It's the story behind the innovations and the people behind the products. It's to find out in a bit more depth about different topics and areas that us as a Global Disability Innovation Hub are working on, and share interesting stories and experiences from around the world, not just from ourselves but also from some of our fantastic partners and colleagues who are also doing some really brilliant work in this area.

The stories behind the innovations and the people behind the projects and products, to find out a bit more about some of the work that's happening globally. It's an informal space for ideas and reflections, and for us it's still quite new, this is the second session we have had, so we really welcome your feedback or thoughts, and as always with these things, every time we do one, we'll try and make it that bit better and take on all your feedback and ideas.

To give you a little bit of an overview of the Global Disability Innovation Hub, so we are a Research and Practice Centre, driving disability innovation for a fairer world. We were born out of the legacy of the 2012 Paralympics, and we are both a Community Interest Company and an Academic Research Centre based at UCL. We work in 25 countries, and

we will be aiming to reach 15 million people by 2022. Our projects and programmes cover a vast array of work from everything from Assistive Technology right through to arts and culture. We also work in Inclusive Design.

Today we are going to be joined today by Vicki, Giulia, Mark and Anastasia and I will leave each of them to introduce themselves as they do their presentation. The set-up of the session is we're going to hear a bit about these four very different areas of work from our panellists today and then we are going to have a bit more of a discussion around some wider open questions before we come to some of your own Q&As. I'm going to hand across to my colleague Vicki Austin who is going to give us a little bit of an introduction into Disability and Stigma, and also introduce herself.

### **Speaker 2: Vicki Austin**

Thanks Louise, lovely to talk to you all today. This is terrifying, much harder than a real life presentation! So forgive me if I make a mistake, but it's really great to see so many people here, friends, old and new, there's some people I spot on the list that were there in the beginning for us at GDI, and some people like Ume that were very helpful in the middle, and some people that we work with now. Last time we had over 180 participants from 34 countries, so I hope today we have as diverse an audience and I hope that the live sessions are accessible to everyone that's trying to reach them.

I'm Vicki Austin, I am the head of - actually, I am the CEO of GDI Hub but I was the Head of Paralympic Legacy for London 2012. I worked for ten years for three different Mayors of three different political persuasions in London, and 2012 was where the idea of GDI Hub started to grow, between myself and fellow Director Iain McKinnon. The GDI Hub way, if you like, emerged from the innovation that took place around London 2012 and it became the driver for our kind of ambition about what was possible, if you bring together determined people, and creative missions to fight for justice. It lit my passion for trying to address issues of disability justice, which I have been committed to for 20 years, but in new and invigorating ways. This session is a really exciting opportunity for me to tell you a little bit of a story; a story of the case study of 2012 around stigma to kick off this discussion. There's lots of work, academic and other, out there to talk about what stigma is, and to describe stigma, and Mark will talk a little about some of that, but actually this session is really focused on what we

can do about it, and how we can overcome it, and that is the GDI way. How do we find new solutions to entrenched problems? So I hope you enjoy the session and see it very much as a conversation in a cafe with your friends.

So the billboard on the image, for those of you that can see it, is a picture that was taken by me, hence the quality of the image, on 12th August 2012. It was the day that the Olympics closed, it was the end of the Olympics for London, and the billboard is just outside of the Olympic Park. You see in the background the Arcelor Mittal Orbit which now has an accessible slide, as well as the stadium and the aquatics centre, and then in the foreground is the bright pink signage that anyone who was in London eight years ago this week will be very familiar with, because it guided participants around the Olympic Park and actually the city.

This poster was important, because I saw it exhausted, leaving work on the last day of the Olympics, we had worked so hard and we had so much to look forward to. Many host cities would have been ready to relax, they had done a great job, the Olympics was amazing, it's time to rest. But not London. Not Channel 4, and not our city. Because we knew, as soon as we saw this kind of tongue in cheek billboard from Channel 4 spring up round the city that we weren't at the end of something, we were at the beginning of something.

This campaign, when I first saw it, with the words "thanks for the warm-up" was such a change in tone to the way the Olympics and Paralympics had been delivered before. It shocked me, I laughed and then cried because I realised we had done something, a little part of what we had hoped for, we had switched a little bit of the tone and the narrative around disability, I don't pretend it will last forever, I don't pretend that we did everything, but we did something, and coupled together with the superhumans campaign, which received some criticism from disabled people, but also challenged a lot of people's perceptions of disability, and the amazing work done by Unlimited, the arts programme in London led by Jo Verrent, (she still leads the Unlimited programme and is on our board), this coming together of what it meant to describe and concern yourself with disability in London, as a positive thing, as an opportunity for celebration and excitement.

It was the first time that kind of slightly cocky confident tone had been taken, and it sparked change. It turned on its head, it gave a new opportunity to the voice of inclusion and for disability justice. Shortly after, London 2012 Paralympic Games sold out for the first time ever. We had more athletes from more countries than ever before. More television coverage, and our Paralympians became heroes around the

world for the first time. It was the most successful Paralympic Games ever but it was also the most accessible Olympic Games ever. And that shouldn't be forgotten.

But I wouldn't want you to think that this spark, this spark that in some ways turned traditional intractable stigma on its head, or the opportunity that overturning it provided, would have been enough alone or would have been possible without a long hard slog. It wouldn't, and that long hard slog didn't start on 12th August 2012, it started in 2005. When a city bids for an Olympic or Paralympic Games, as I said on the IOC video they have just made, they get a chance to choose what type of city they want to be, how they want to be known, what's their mission, what are they for?

London chose to be for the inspiration of a generation of young people and accessibility and inclusion. And those ideas were hard-baked into everything London did, from the bid through to the surprising win in Paris, through to the delivery of the event. And I am reflecting more and more, as I think about our work now - in 25 countries, about what enabled that change, what was the fire that we had to build that was possible for the spark to light it? And so this methodology, which is very much a work in progress, in fact this is the first time I have put it on a slide publicly. It involved hard work.

First, it involved a really bold, well-scoped mission, which was clearly and repetitively communicated, about what type of relationship with disability London wanted to have. Second, it involved political leadership from three different Mayors. Third, our objectives were clear at a programme level, so everyone knew what they had to do, and they were managed. We had really open partnerships, so everyone, be they a child in a school in Newham being taught the Paralympic values, or the Mayor of London, who was Ken Livingstone, then Boris Johnson then Sadiq, were able to understand what they needed to do to make disability inclusion a reality.

We had skilled and diverse teams, I hope I was slightly part of one of them. But it was necessary for everyone to have technical assistance to know what to do, whether they were a private sector company bidding for work, or the group responsible for security on the park. We encouraged innovation, and actually Iain was part of the team that designed a newpool lift prototype, not the one that went in, but the one that came second, and so kind of thinking about how, for example, disabled people get in and out of a pool was something quite new. We had data and reporting that took account of disability, so that we could measure our programmes and our success. There was lots of

media engagement and success was championed, but there were also consequences to failure. Senior people lost their jobs if they didn't take this seriously, and that mattered. And community engagement, and I don't just mean with disabled people, but disabled people in the communities of East London was present at every stage. Lord Chris Holmes, our first chair, was the director of Paralympic integration so the leadership of disabled people through the process was essential. So that was our little case study, our story, our kind of fire that we built nearly ten years, the pieces, the twigs, the wood (I am probably extending my analogy too far) that we needed to pile together so it was ready to light, and then the light, the touchpaper, the cultural shift that enabled that fire to burn at London 2012 when the campaign hit and the attitudes shifted. That for me was the importance of our story, something, that kind of spark of change, that can continue to be sought now.

We know a broad coalition, as well as a long-term plan, is important and for me, to conclude, disability innovation means building that fire, especially now when times are hard, and funding is short, and COVID is really difficult. Now is our time to build the fire, and to put in place the long-term change that we need by developing the tools and the partnerships and the networks and that's what we intend to do, and we hope that you'll join us.

### **Speaker 1: Louise Gebbett**

Wonderful, thanks so much, Vicki, I think that's really interesting, and for me the elements that come through really strong there is around the importance of building momentum, and actually how a one-off event such as the Paralympics has such a large impact. Not only during the event itself, but also followed on from that, it's more a one-off event, it's around the strategic thinking and strategic approach – what needs to be put in place from the starting point to really enable the best outcomes and the biggest impact, for not just those involved, but also a much wider cultural change in how people are absorbing that information, and how they go about their daily life and their daily activities.

It has been really fascinating hearing about all of those, and how such a major moment, in the culture of London and of the UK has really been a starting point for something much bigger and something that we're continuing to grow and take forward and really build upon.

So I think that's a great point to hand across now to our second speaker today, so we are going to go on and hear from Dr Mark Carew, Mark I'll

leave you to introduce yourself and tell us a little bit more about your area of expertise.

**Speaker 3; Dr Mark Carew, Senior Researcher, Leonard Cheshire**

Thank you Louise. My name is Mark Carew, I am senior researcher at UK-based disability organisation Leonard Cheshire, so we work in over 54 countries to advance disability rights.

In the next seven or so minutes I'm going to tell you a quick story about what innovation in stigma and discrimination research has looked like in the past. Stigma and discrimination is one of my research areas at Leonard Cheshire, so I am going to cover what it looked like in the past, what innovation in that area looks like now, underpinned by some of our work from Leonard Cheshire.

First of all, imagine that you're a non-disabled university student in the 50s, 60s or 70s, when a lot of the initial stigma research was done, you sign up to a research study on stigma, and you're paired with a disabled person, and the study looks at how well you complete tasks with them, so co-operation being a hallmark of a positive attitude. Well, chances are that the other person who built be a non-disabled confederate would actually be a non-disabled confederate, another student pretending to be disabled at the direction of the experimenter, to give the experiment a bit more of the control, in terms of the research design, so a modern equivalent of that, looking at stigma, is to simulate an interaction between different social groups with computers, so perhaps the person on the other end of that is a AI or perhaps it's a non-disabled confederate again, it doesn't matter. Such research designs, they are scientifically innovative, but they are not inclusive.

A more inclusive and natural approach to investigating disability stigma would start by asking disabled people about their experiences of it.

So it might surprise some of you to learn that this has not been a common approach historically in prejudice research. If we take one of the best known and empirically supported prejudice interventions, Contact, that is the idea that having interactions and particularly friendship with people who are different to us changes the attitude to the wider social group. When you look at all the 550 studies done on contact interventions from 1954 to the year 2000, it shows both that disability is an understudied context for stigma, with just 76 studies, but

the real kicker is that only a handful of these studies look at the perspectives of disabled people. So with a body of research like this, you can say, OK, contact with disabled people changes non-disabled people's minds but the problem is that it is not knowing how the same interaction was experienced by the disabled group. Was the same interaction viewed positively?

Let me tell you that these experiences often converge in real life, so people with disabilities will know the behaviour of invasive advice, so that's where somebody offers some well-meaning but unsolicited suggestions, so they might come up to you on the street, one that I have had personally is "try some spray to fix that", I have got cerebral palsy, it's a neurological impairment, it's not a mosquito bite or something. So when that happens, you've got a choice to confront or avoid prejudice, but we disabled people, we're important and we're busy, so often we might not just go along with the comments to end the interaction quicker. So the non-disabled person goes away thinking, "What a friendly bunch disabled people are, I might talk to more of them", and actually that shows what a helpful person I am", but for me, my experience, I haven't had a nice encounter at all, so intergroup interactions like that are fraught with misconceptions and miscommunications, so there is very robust academic literature around that. The best research approaches will seek to look at majority and minority group perspectives, ideally in the same study but at least in the same research programme. In doctoral and postdoctoral work, I did research like that, we conducted what I think is the first empirical test of the impact of naturally occurring exposure to Paralympic media among both non-disabled and disabled people, and we found some evidence of a positive attitudinal shift, but we didn't find substantial group differences.

But it's important to check that. Just because an intervention may have a positive impact on non-disabled people's perceptions of interactions, we still need to check if that links up with disabled people's experiences as well.

Now we have another innovation mandate, and that is to ensure that the process of research is disability inclusive, so the research must be inclusive across the life cycle of evidence generation and that's from planning through to methodology right through to dissemination, and that's a rights issue. Like infrastructure and services, any research study

must be accessible to all disabled persons who are eligible and might wish to participate. And also decision-making about what research to do and how to do it, and what to say about it, must involve disabled people. And that makes the research better.

For example, in our GDI Hub funded research for AT2030, looking at overcoming stigma towards assistive technology in Kenya, our starting point to plan the research was talking to DPOs, that revealed some insights such as it's not the intrinsic quality of assistive technology, like it's shape or size, although that might play a role, that predicts stigma or causes concern about stigma. It's the fact that the use of AT, the perception of that for some disabled people is it makes something about ourselves visible, and it's particularly how the worries and the concerns about how non-disabled people might interpret that difference, so with that, I'm mindful of the phrase that - as commonly said by non-disabled people, wheelchair-bound, whereas disabled people commonly think, OK, what's trapping about a wheelchair? It's enabling, it's what is used to go places and participate in society.

So disability inclusive design, research design is a rights issue but it's also an innovation mandate. Take COVID-19, it's made science go fast, but our business as usual research practices are disrupted. We have to find new ways to ensure that disabled people are included throughout research, so for example, in remote COVID-19 evidence generation. And that's what Lenard Cheshire UK aid funded innovation to inclusion employment programme did.

Our immediate reaction to COVID-19 was to say, OK, how can disabled persons' organisations lead this process? So we implemented a research study in Kenya and Bangladesh - you can read more about that via our website. What we found in terms of stigma specifically was actually that many disabled individuals in both countries are experiencing increased rates of stigma during COVID-19, so the example I am giving from Kenya is 39%, and when we delve into the qualitative data we see three themes emerging;

Some participants are considering COVID policies ableist themselves, so I've given the example of how is somebody supposed to transfer from a wheelchair while social distancing? So others that are finding stigma from - explicit stigma from non-disabled people, either because non-disabled people are thinking disabled people cannot follow hygiene

standards, or because non-disabled people are confusing physiological symptoms of certain impairments with COVID-19 symptoms. And that's leading to stigma and discrimination.

In summary I just want to reflect how far we have come in terms of innovation in stigma research, so researchers, as I showed on the first couple of slides, they used to jump through hoops to design research that didn't involve disabled people, very innovative research but it didn't involve disabled people, and that wasn't, I think, through explicit prejudice, it's likely as a function that there was less disabled people around them in the research environment to say, "Hey, there's another way", because of the other barriers like infrastructure barriers.

Now when we speak about innovation, it's more likely to be towards research design that looks at stigma from the perspective of both majority and minority groups, both non-disabled and disabled people, which is crucial, and to support a rights-based perspective, we also need to ensure that stigma research, like any research, is fully inclusive, and in challenging times like COVID-19, especially, we have an innovation mandate there. Thank you for listening.

### **Speaker 1: Louise Gebbett**

Thank you so much, Mark. Really interesting just to hear all your reflections and those different areas of research done by yourself, and wider across Leonard Cheshire as well. I think it's really fascinating, you have really highlighted why stigma is so significant and so important for everybody to be aware of and recognise its impact, and sometimes those impacts are really dependent, on the area and the topic and the region that that work or that research is happening in.

I wrote down a few words as you were talking that came across really strongly to me, and that was miscommunications, that actually two people in the same interaction can come across with a completely different perspective of what that interaction was like, and that's something that myself I had never given a huge amount of thought to. The kind of perceptions between different people and assumptions that I think as people we can all make sometimes, and the importance of being aware of how those miscommunications and perceptions and assumptions can feed into stigma and can impact huge amounts of different areas of work in disability innovation but also far-reaching beyond that as well.

I know we have had a couple of questions around how people can find out a little bit more about your work, Mark, so the presentation and this recording will be available after the session and we'll also put out some more information & links.

Anastasia, and I'll leave you to introduce yourself in a little bit more detail, to talk about some of your work around youth in Kenya.

#### **Speaker 4: Anastasia Mirzoyants**

Great, thank you very much for having me and just to quickly introduce myself, I am the head of knowledge and learning at Shujazz Inc, I will talk more about Shujazz Inc on the next slide but generally it's a social venture that's focused on young people aged 15-24 in East Africa, specifically Kenya and Tanzania. What I am going to talk about is how we approach the issue of disability when it came to young people, working with young people, and specifically shifting norms and behaviours among young people in Kenya, and learning about what shapes the knowledge, attitudes and practices of young people, and also what contribution can we as Shujazz Inc make into changing the situation?

So here is a little bit about Shujazz, as I mentioned, it's a social venture, we have several platforms that are youth-centred and geared towards helping young people. Currently we have 7.5 million young people who follow Shujazz in one way or another. That's 56% of all youth in our age group, 15-24 in Kenya, 23% in Tanzania currently. One of our leading ventures is Shujazz media platform, so this is the platform that includes several media channels, from analogue to digital, and this is the platform that we use for social and behaviour change communication. So this is a platform to which we invite young people as a safe space, where we can surface sensitive issues, challenges they face in their everyday life, and then see how we can help them find solutions among themselves. This is really important for us, because we don't want to be the instructors, we don't want to be people who tell the youth what to do, we want them to collaborate and partner with each other, regardless what the issue is, and find the challenges that would be genuine to them - so that there is a buy-in and that there is an uptake of communication around norms and behaviours that are more positive than they used to have before.

For us to be able to do so, we do quite a bit of research, and all of our media campaigns are strongly grounded in all of the research that we

have done. And because of this very strong interlink between research and media, and then media and research, when we build the feedback loop, and let young people tell us whether we did well with our media or not. Based on what we learned from them, we were able to grow the platform and also along the way we won quite a few media awards, including two international Emmys.

When we started our partnership with UCL last year, we talked again about doing research involving our media but turning this partnership more into a partnership about conversations on what's currently happening with young people with disabilities in Kenya, what's currently happening with young people who are not disabled but interact with young people with disabilities. Is disability on the radar for young people?

So we approach it from the perspective of: can we do our typical traditional research that we would do with any media campaign before we started, formative research, and just to understand what's happening in this space. In terms of research that we generally do, we countered with understanding that we are working with young people, the attention span is very short, some of the issues we want to discuss with them are extremely sensitive, so it never works asking direct questions.

About ten years ago, when we just started our social ventures, we invented sort of a research focused experience for young people, where they come together and do fun things, entertaining things, but along the way it helps them to build stronger relationships with our research team, build rapport with research team, and really surface conversations in a way that would not as if we just had, let's say, focus groups and asked them direct questions, so we play a lot of games with young people during our research, we make them draw, we make them write poems, we make them dance, we make them play out scenarios, all of that with the goal of creating this space similar to street theatre research, where we invite young people into the space and play out situations and then analyse the situations.

What it lets us do is we create segmented groups of young people and we try to understand them in that, and then place them along the rejection/adoption scale, where we know which particular segments of young people, for example, are in the resentment/rejection space, what they know, how they know, what their social norms are, who are the influences around them, who are the people who are in the adoption

space, whether it's normative or behavioural adoption, how they got into this space, what is different between those in the rejection and adoption. Then we define and devise the journey for young people in the resentment/rejection space to move forward and join the group with positive behaviours.

I have an image of what were the outcomes of our experience with young people that we call ground truth, because it's the truth from the ground, so there are four different segments of young people, as you can see. So there is a segment of frowners, so these are young people who are extremely negative about people with disabilities, they are young people with no disabilities, they are the subject of a number of myths, stereotypes, stigma, overall they are very resentful of the presence of people with disabilities in their social circle.

There is a segment of profilers, which includes both young people with and without disabilities, and this is the group that are not necessarily negative but they do profile each other, people with disabilities profile young people without disabilities, and the other way around, and they adjust their behaviour accordingly in a very visible way that makes both of them very uncomfortable.

There is a segment of comrades, young people who engage with - so both young people with and without disabilities who engage in a very positive manner, in a normalised manner, and there is a group of supporters who again are young people without disabilities who try to take a role of supporters, protectors and enablers for young people with disabilities, and when we are looking at what defines these different segments, we arrived at several factors but just to highlight two. One of the really, really important factors was whether or not young people were growing up with people with disabilities present in their routine life. So what we find, for example, in Mombasa, young people were telling us, "You know, I go to school and my class mate is disabled, or my teacher is disabled, and I go to church and there is another person that I know and I'm quite close with who is disabled", and the same young people with disabilities were telling us, "We interact in school, we interact in normal everyday routine, we go together here and there", so this presence of young people with disabilities in the everyday context in a positive way, were the two factors that defined the attitude of particular segments to people with disabilities and people with disabilities towards

young people, so the presence and the visibility and the specific context of the visibility, whether it was positive or not.

In contrast, what we found in Nairobi, for example, was that people with disabilities are extremely visible, however they are visible in a very negative context. So when we asked young people without disabilities to tell us where would they see people with disabilities, they would say, "Well those are beggars in the street", they might pretend that they have disabilities so that they can scheme you, they can lie to you, they can get some money out of you, and that also was the factor that, as Mark referred to, that was creating different experience for people with disabilities as well, where they said, "I feel like I am taken as a representative of everybody who is a people with disabilities, so if somebody had a bad experience with a beggar in the street who happened to be in the wheelchair, then they would say everybody who is in the wheelchair is a really negative person and is out there to get you and to scheme you". So all of these life experiences, the normalisation of the presence of people with disabilities in routine life, the positive experience and the positive engagement, the positive context around that, seemed to be very important.

In this regard, for example, we realised that frowners were most likely to be found in rural and deep rural areas, so these are young people with a lot of resentment and stigma against people with disabilities. Because of the mere fact that in rural areas, disabilities, especially in the areas with young people which we interacted with, was perceived as a curse, something that can spread to other people within the communities, so generally you would not see people with disabilities being out and about, they are usually hidden in the house, so nobody knows, because having one person with a disability in the house affects everybody else in the household, so the girls wouldn't get married and the boys wouldn't be able to find a job because of this fear, stigma and myth.

Based on that, then our approach was that we want to change - we want to focus on two segments, we want to focus on frowners, the young people who are not exposed to people with disabilities, and showcase to them the normal everyday life where people with disabilities come as innovators, as experimenters, as creative, as fantastic contributors to the community. And similarly work with the segment of profilers, both young people with and without disabilities, and showcase to them how they can work together, be together, without trying to

extend their first impression about each other for the entire population of young people. Our idea was we want to create comrades and we want to create supporters among our young people. So this is kind of the view of all of the media that we have on the Shujazz multimedia platform, so we engaged our comic, SMS platform, events, social media pages, and also the network of 3,000 distributors, to start telling stories about very innovative, interesting young people who are contributing to their communities, who are part of their routine lives of their communities, and who are just genuinely great young people, and that involved telling real stories of young people with disabilities, shows showcasing role models and positive deviance, as well as fictional stories.

I have two stories of two of our fictional characters. In our story wall, so this is in the comic and then throughout social media, we have one character, which is called Sifa, who is an agricultural innovator, so everybody comes to Sifa in their community, she is a role girl and everybody comes to her because her garden is consistently flourishing and she is making really good money from her agricultural hustle. So what we do in our stories, we don't focus on the fact that Sifa is a young lady with disabilities, we focus on her skills and her contribution, showcasing how Sifa is actually a great hustler and everybody can learn that she is a great hustler and she is happy to teach everybody, so the whole fact that she is disabled is not that important in the story.

However, it is in the background, it creates this normalisation of Sifa being present in all of the activities with her friends, but Sifa also being really good at something that her friends are not. And another character, who is Laro, Laro is a albino and he is part of our life story in a slightly different way, where he is going on a date with one of our quite popular characters, the lady, and what happens during the date is that they see a little boy drown in the pond, and Laro jumps in and saves the little kid from the pond. So again, the discussion is around Laro being a really great gentleman, taking his girl on a date, and showcasing how great their relationships are, but also presenting Laro as a really cool guy who can save a kid and contribute to the community this way. So overall, this is our approach, our research and our approach in talking to very specific groups of young people, knowing very specific routes of their misconceptions, with stigma and worried attitude towards each other, and then retelling their stories in comic stories through either fictional characters or real-life young people. Thank you very much.

### **Speaker 1: Louise Gebbett**

Thank you so much, Anastasia, that was really, really interesting and amazing to see some of those fantastic graphics and approaches that you have taken. I find it really interesting that the absolute core to a lot of your work is putting the youth at the heart of creating and designing that content itself, and really driving it so that the output is really, really targeted to your target audience. Who are very much involved in shaping of that, and how that really supports in breaking down some of those issues and barriers and I guess their perceptions that have been formed through their environment and through their potentially quite limited life experience, and how actually through this a creative, dynamic and quite an innovative approach, you can challenge some of those, in almost quite a subconscious way. It's really fascinating and I would be interested to hear a lot more about all of that work.

I will now hand across to my colleague Giulia, who I will let introduce herself and talk a bit around assistive technology and stigma and looking at identity.

### **Speaker 5: Dr Giulia Barbareschi**

Hi everyone.... So if you speak BSL, I sincerely apologise for the particularly bad quality of my signing. If you don't speak BSL, what I just did was I introduced myself, I said my name was Giulia, and that my sign language name, it's indicated with this sign. The reason for it is because if you really have met me at any stage, regardless of weather condition, day or night, indoor or outdoor, there is a very good chance I will be wearing sunglasses on my head, it's a habit that I picked up many years ago, and it kind of stuck with me. This is a very simple example of how a relatively minor detail of my physical appearance influences my identity so much that my sign language name kind of picked it up. This is a really common thing, it happens to all of us all the time. How we introduce ourselves, how we present ourselves, the way we look, has a huge impact on how people perceive us, but also a lot of time on how we perceive ourselves. Unfortunately though this is almost never considered when it comes to assistive technology design.

Assistive technologies are designed for functions, they are created to build a functional gap between the capability of the person and the capabilities that are required to complete a certain task in a certain environment, usually in a certain way that is dictated by mainstream society. Now I'm very familiar with function, and actually I'm very fond of

it, in many respects, before becoming researcher, I was actually a physio and I worked on wheelchair services for several years, which is why I was really excited in 2019 when I got asked to work on the Innovate project with colleagues from Motivation.

The Innovate project is based around the idea of combining digital manufacturing techniques, things like computer modelling and 3D printing, with traditional manufacturing, to create customised bespoke wheelchairs for clients in Kenya. This is huge, and it has the potential of being revolutionary, and I was really excited by this project. Our assumption is that having access to these customised wheelchairs will give people much relative advantage, so they would be able to do more things than they were with their regular wheelchair, and they will be able to do them better. So function is really what we had in mind when I designed the research protocol to evaluate this project, and yes we used both quantitative methods, so things like wheelchair skills test, but also qualitative methods, such as interview, but what we are really after was really around what advantage in practice does this wheelchair give?

One thing is that everyone that I worked with on this project, and everyone that participated to it, really was hugely invested on it. Which is why the most disappointing moment of all came bang in the middle of it. The most disappointed moment for me happened with Salome, who was one of the participants of our studies, she was super-excited about the project, she came over, go the assessment done, and then she went home, we made a wheelchair just for her, came back two weeks later, she transferred on to the wheelchair, and the wheelchair broke. So as you might be able to see from the picture on the left-hand side, with the red circle, as soon as she transferred on it, on one of the 3D printed joints, very close to the rear left back wheel, a very, very small crack developed. Unfortunately that is sufficient to make the wheelchair unsafe. So we weren't able to let her test it properly, she had to transfer back to her own wheelchair and that was it. Regardless of that, we decided to do the closing interview anyway.

Honestly, I have to admit, I was massively looking forward to doing it. Generally, interviewing participants is one of my favourite parts of my job, it's something that I really like to do. Interviewing a very disappointed participant, especially when you feel somehow responsible for the failure, it's really not a particularly pleasant experience. But what

emerged from it during our interview was that she actually loved the project, and for the life of me, I could not figure out why. Initially, I thought she was trying to be nice. Unfortunately sometimes this happens, people try to give you the responses that they think you want, not really what they think, so because of that I started to prod a little bit deeper and see exactly why did she like it, because in my eyes her experience was a complete let-down, and as we were talking she said this: "Getting my wheelchair made me think of going to a tailor, a tailor will fit the clothing according to my body, according to my style, according to my taste. So I like this about a wheelchair as well. I like that I get asked what colour do I want it. To me it matters so much, it's not just a sitting thing, I want a chair that when I use it, when I get to places, it doesn't make me look miserable. I don't want to look miserable because I'm not miserable".

So when she came up with this, I was a bit thunder struck genuinely, and after we wrapped up our interview, I went back and looked at all the other interviews that we did before, as part of the project. And surprise, the same thing kept emerging over and over again. I just didn't see it before, because I wasn't looking for it. And what emerged is that function yes was important, and there were loads of accounts of people telling us what the wheelchair did well, what they didn't do well, what it had to improve, but what caused them to really buy into the idea and be really enthusiastic about this project was the fact that the way the wheelchair was made allowed them to self-express their identity through their assistive technology.

So really in the end we decided that it was something that we had to look at in more details, so at the very end of the project, we got all the users that took part in it to come together and do a group interview specifically around this. What they told us is that function was crucial for wheelchairs, you use wheelchairs to go around, so having them working well is important. But what they strongly believe is that function could be something that can be iteratively improved through design, and that can get better over time. What can't get better over time, what is either there from the beginning or it isn't, is the principle of being able to affirm your identity, to self-express yourself through your wheelchair, and that you only get through an approach that allows you to personalise as you go. That can't be retrofitted, it's either there or it isn't. Ultimately the thing that all our participants said is until we acknowledge that it's fundamentally important for assistive technology to enable the people

that use them to present themselves, to look and to feel the way they wanted, what we're going to provide, it's technology that projects the wrong image about people, and that's really ultimately, in their opinion, what stigma is really all about, so thank you.

### **Speaker 1: Louise Gebbett**

Brilliant, thanks so much, Giulia, for sharing those stories and I think what's really interesting there is that actually the output that you had from that experience was quite different to what you were going into expecting and the type of feedback and the type of response you were anticipating from the testing of that assistive technology. The huge importance of the sense of self, and choice, and options, and I think that really aligns with stigma, not just through assistive technology but lots of different areas, and shows where innovation, design, culture and art can come together, and can start challenging some of those elements of stigma. Thank you so much for that.

We're coming to the end now of our panellist sessions but we have had lots of questions come through on the Q&A and the chat box, so thank you everybody for your inputs. There have been quite a lot of people asking about how they can find out more information and get more involved and discuss some ideas further, so we'll provide some more information after the session on some options for that, but I just wanted to answer a few of the questions directly, so I will pick up a couple of them and ask our panellists to come back with some responses.

One of them, Vicki I am going to come to you first for, was 'how should we and how could we go about really lighting the spark of innovation in this area, around stigma, within disabled communities themselves?'

### **Speaker 2: Vicki Austin**

Thanks, I think I just tried to answer that in words. It's my experience that when disabled communities are able to be listened to, often that innovation is already lit, often times disabled people shouldn't have to, but especially in lower-resourced settings, do have to be very innovative and creative in terms of solution finding. Often times the barrier is the willingness of those with resources and decision-making power to actually listen to that group of people, and so one of the ways we have

been successful, given time, has been to enable spaces for disabled people in those settings to come together and actually be collective around their aims. One example, I'm working in Sierra Leone at the moment with Development Planning Unit at UCL and we found disabled people living in some communities who hadn't actually spoken with each other collectively, never mind collectively articulated their aims, and their goals. And once they met together, they were able to have much more recognition from the community, and actually some of those people told me that access to assistive technology was a secondary concern to them, being able to be active participants and belong in their community, free of stigma - was their primary concern - so as an example, that's somewhere we have been working to address it.

### **Speaker 2: Louise Gebbett**

Thank you Vicki. I am aware of time, we have just gone slightly past two o'clock but I am just going to ask a couple of questions for our other panel members, so we have addressed some of the brilliant questions that have come from yourselves as audience members.

Mark it would be great to come to you, we have had quite a lot of people interested in hearing some more and reading more about your research and one of the questions that came through was: 'how should people or could people best go about involving disabled people, and particularly where there might be restrictions on projects to do with things like time or resource' do you have any advice or guidance on what you think is the best approach?

### **Speaker 3: Dr Mark Carew**

Thanks Louise. I tried to get at that a bit in the chat box, sorry I'll turn my video on as well. So I think that it needs to vary context in terms of the approach to involving disabled people but I think a key starting point is to actually have that conversation at the outset, to actually ask disabled people and prospective partners how they would like to be involved in research. Another very important process for that is the process of reflection, so at the end of partnerships, or important points, make sure that the process of reflection is built in. What has worked well in terms of inclusion and what has not, and where are the bottlenecks. I did post it in the chat, I think UNICEF have just released a brochure, a guide that

talks about some of this as well, that people might like to look at. Thank you.

### **Speaker 1: Louise Gebbett**

Thank you Mark, I appreciate that was a very big question to ask when we're already over time, but it's just good to get a bit of a perspective from yourself on that.

Anastasia, we have had a few people just asking around if you think it might be possible for people to I guess recreate or take learnings from some of the approach you have made in terms of the engagement of young people within Africa, whether you think that's a model that could work in other places, potentially in Africa and beyond? and I guess also we have had the question of whether a lot of work you're doing is based around this concept of positive normalisation of people with disabilities, and whether you think that is a summary of what you do or if there's a different way you would describe it.

### **Speaker 4: Dr Anastasia Mirzoyants**

So I think I just responded to that question. It's not necessarily just positive normalisation of people with disabilities, because what we want to achieve is not just say that people with disabilities deserve special treatment, because that's again putting people with disabilities separate from everybody else, what we want to normalise is interactions among people regardless, whether they have disabilities or not, so that's the reason we embed characters with disabilities across our Shujazz world, rather than create separate stories, where we just tell the story of Sifa, for example, and her life, but Sifa appears in the life of all of our characters, and it's just a normal presence in there - so I think yes, it is positive normalisation, but not of people, rather interaction among people regardless what their personal characteristics might be.

Regards to the engagement with young people, so as I mentioned we do work in Kenya and Tanzania, specifically these are our home markets, but we also tried this engagement, the experience with young people, research-focused experience, in Uganda - it went really well, we got reports from young people in Uganda and Cameroon that they had received our comic from some of their friends, they couldn't understand what's in the dialogue, they understood the stories though, they really

wanted to - us to try and bring the comic and the platform to their countries. We are thinking about Rwanda.

So we think there is the potential of taking this to other countries, we are just not sure which specific countries, and COVID-19 kind of derailed us in our thinking a little bit. But yes, that definitely has been on our radar, that that would be an interesting and beneficial venture. So if there are specific suggestions and we can discuss. We are happy to discuss them

### **Speaker 1: Louise Gebbett**

Wonderful, thank you for that.

So Giulia, just as we're starting to close, I think we'll just come to you with one final question before we wrap up the session. So we have had a few people question around the idea that assistive technology – AT - has the real ability within itself to potentially reduce stigma but also beyond the actual product, what might be the opportunities for other products, or design and service delivery to create such change? It would be interesting to hear your perspective on what the other opportunities might be on there.

### **Speaker 5: Dr Giulia Barbareschi**

You're definitely right, there is huge opportunities on service delivery and if anything actually, service deliveries and how assistive technologies are provided is what makes a difference, because a lot of time things can be provided as part of a process, and in order to capture even what the person wants from an assistive technology in terms of affirming their personal identity, expressing themselves, or even modify according to their preferences the way they are seen and perceived by others, that really has to start on how technologies are distributed, how people come in contact with them.

At the moment there is a very top-down approach where your possibilities of choices are very limited. And the best that we can hope from a lot of it is to make things as unobtrusive as possible. I am not very fond of this idea of unobtrusiveness because it almost passes the message that there is something to hide, something that doesn't have to be that visible. In reality, you have to give people the choice of having something unobtrusive if they want, because in certain contexts that's how they might want to be perceived, but in others they might actually wish to be very visible and they might want to push up their identity, and

they will have to be given the instruments to do so in the way they want, and that can only be baked in the service delivery. It cannot just be there in the device alone.

### **Speaker 1: Louise Gebbett**

Thank you Giulia. I think that's been really interesting, and it's been really fascinating just hearing from all the panellists on today's session, so a huge thank you to everybody for taking the time and joining but a massive thank you to all of you joining from around the world.

We just wanted to let you know before we wrap up that our next Disability Innovation Live session will take place on 17th September and that session will be looking at Product Narratives, and that's really taking a look in a bit more depth at specific assistive technology products such as eye glasses and prosthetics, and looking at the challenges of supply and demand side barriers for priority assistive technology, so we'll be hearing from some real experts in that area and what the potential is to improve access globally for those key assistive technology products and bits of equipment.

Before we wrap up for today I'll hand back to Vicki to see if she wants to finish off with any final words of wisdom around disability, stigma and innovation, today has been a fascinating discussion with lots of different perspectives and experiences, but Vicki it would be really good to hear if you've got one take-away for everyone to go away and think about as a learning from today, on how we can take this forward.

### **Speaker 2: Vicki Austin**

Of course, a couple of things. The power of young people to drive change, how important it is to focus on the next generation, which range true in London too. The importance of stories, in telling those stories ourselves, and enabling others to tell their own stories. And the importance of participation, especially in the way we envisage things like research. And finally the power of technology to drive change, so I'll probably comeback to where I started, which is let's build the fire, so that we can take every opportunity to light it.

### **Speaker 1: Louise Gebbett**

Wonderful, thanks so much, everybody, that's the end of our Disability Innovation Live for now and we hope to see you all in September for our next session, goodbye!