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RI World Congress**26 October 2016****Plenary 4 – Independent Living and Social Care**

CHAIR: Thank you very much. Welcome back everyone to the main room. I hope that you have engaged, contributed, learnt a lot from the parallel sessions that were run before and after lunch and I hope you have made some new and old friends after lunch.

One quick announcement, and several have been asking this: there is no restriction on bags tomorrow. So, if you are packing up and leaving to go home tomorrow, please bring your suitcases tomorrow and there is will be an appropriate place if you go to one the volunteers that will advice where to leave it safely.

We are moving on to the last session today on independent living and social care. I was due to be joined by Mike, but unfortunately he has been taken unwell, so apologies, it's me again.

It's a delight to introduce Tom Shakespeare to you. Many of you will have already known of Tom or come across his work. He is going to focus on a subject he did some research on a while a go now, but we thought time resurrect it.

TOM SHAKESPEARE: Thank you very much indeed. It's a great honour to be back at RI. Today I am talking about disability and sexuality. Twenty years ago I did a study of this topic. Because it's back to the 20th anniversary, I had been back to interview some of the people I spoke to 20 years ago. But I will talk about that and go a little bit further.

Where are we coming from? Well: stereotypes. That is stereotypes about disabled people, as in so many other fields.

We are asexual. What else? May be that we are unrestrainedly sexual. In many countries around the world there are these taboos, the ignorance about disability and sexuality and yet as we look to equal rights in many different fields, if sexuality is part of life, it should be part of our lives again.

This book I wanted to highlight: 20 years ago we went out and talked to more than 40 disabled people. We wanted to hear from them about sex and love, the good, the bad and ugly. And, the summary of the book is that disabled sexuality is a problem not of how to do it, but who to do it with.

What I did over the last few years is to go back and talk to people. They are obviously 20 years older, and the good news is they felt stronger. They felt emotionally stronger. They felt more in their bodies. Also, that they were less noticeable as disabled people, because, of course, everybody, all their peers were older, and they were older, and disability was less salient. They didn't stand out as much.

They had sex. They had relationships. They talked about how the Internet was a new thing that was not there 20 years ago which had tremendous potential to liberate people. They also talked about austerity in Britain and other high income countries which really restricts the independent living and choices of disabled people, including choices around relationships.

The women said to me, "You know what, men, when they are young, they want a trophy bride. They want a beautiful young woman" but, as they age even men get wiser and they realise that actually they want somebody to talk to; and it does not matter if you are disabled or not, so it's good things and bad things that these folks experienced in their lives.

This is a little bit about disability and sexuality around the world: what we found from social research in many, many countries, and I am naming half a dozen or so here, is surprise, surprise: throughout the world disabled people are having sex. These are studies with disabled people. So 70-80% of disabled people have had sexual and emotional relationships.

Even people with profound disability had had sexually and emotional relationships. May be, you don't need me to tell you this, or may be you do, or may be you need to go and tell the rehabilitation professionals, the policy and programmes in your country that disabled people are having sex so they need all the things that go with sex: Sex education; contraception and abortion; privacy. Many people living in residential institutions are getting no privacy. Legal change; in many countries it's still illegal for a disabled people to get married because they are believed to be unable to consent.

So there are loads areas where this evidence and other evidence from around the world should inspire you to go back and do something.

These are needs and unmet needs and I have mentioned some of them.

We live in a world where HIV is still very common and disabled people are at risk of HIV and sometimes disabled people are targeted because they are thought to be at low risk, and guess what? Then they get HIV.

Sterilisation: when I worked with WHO, we had a report about sterilisation. Disabled women in particular are still becoming sterilised against their will, particularly women with intellectual disability.

We have not begun to talk about reproductive and maternal health. Disabled men and women have children too. They want to be supported to look after their children; not to have their children taken away; not to be left to struggle without support.

So, I didn't have to put sexual reproductive health at the top of this slide. These are the problems, to health care to any disabled people.

Information: do people know what they are entitled to?

Attitudes: and the pregnant disabled woman that turns up to the hospital in Mali, she is there and laughed at before she gives birth: "How do you get pregnant" they said? That is a true story.

These attitudes throughout the world are evident.

So we need to empower disabled people in the area of sexual and reproductive health as in all the other areas.

This is a Human Rights issue. We know the Convention on the Rights of Persons with Disabilities and the other Human Rights treaties mention sexual health, reproductive health from everybody. We know the Convention on the Rights of Persons with Disabilities in Article 23 mentions respect for home and family and Article 25 in health; it mentions sexual and reproductive health above other things. It's not optional for hundreds of countries that have ratified the country; this is obligatory and we should residential institutions to account, and holding legal services to account because these are part of our Human Rights.

So, what is needed?

Get off our backs. Let us get on with it. That is, in a way the native freedom. But also the positive freedom: remove barriers. When we are offering services are we enabling people to meet friends, let alone as lovers?

Is there privacy for disabled people living in supported accommodation?

If there is a disabled transport, are you allowed to take your boyfriend or girlfriend on the bus? Or is it, "Oh no, no, it's just for her/him".

We deliver a whole lot of stuff to disabled people and we need to make sure we deliver in ways that include.

There is a fantastic book: our book came out in 1996 and this is about sexuality in the Nordic region for disabled people, and it raises a lot of questions. So if you are interested in what I have to say, read what I have to say.

I wanted to do an overview about what we hear and see about sexual reproductive health services around the world: it's not just high income countries that these services exist.

When I was at the WHO, two of our interns did projects looking around the world and they found a cross-section; it's not all of them by any means, but they found dozens of projects. And I wanted to highlight one project very briefly from each region of the world.

In central Asia, Incas stand, in Almaty, this project working was with women with disabilities in that country and promoting reproductive rights and raising self-esteem.

In South Africa, a deaf HIV awareness project, aimed at deaf gay men and lesbians.

Those little boxes are highlighting how some projects are mainstream and extend to disabled people; some are disabled people's organisations that are taking on sexuality, and there are different ways to do it, and these are examples of these types of projects.

From Brazil, from Sao Paulo, here, this is people with intellectual disabilities learning about sex and bullies, and the reproductive cycle.

From India, in Delhi, a really interesting disability project that has a help line, and they train their help-line advisors so they can meet the needs of disabled people. Sorry, it's a sexuality project when they have trained their counsellors about disabled people's needs.

Another project from Delhi: they have done Conferences; they have done training; they have done research. They are a women's health project, and they have particularly made all their work accessible to disabled people.

So projects from every WHO region: very diverse projects. I wanted to just give you that quick overview so you would think it's not just a British issue nor Scandinavian issue but global issue at every corner in the world where people are belatedly doing something about the sexual health and rights with people with disabilities.

We have the same sexual needs as everybody else. We have the same dreams and aspirations. In the past people said to me "What do we want? We want a job, partner, family, and that is what disability inclusion is about.

The Disability Rights movement have been pretty good at trying to get people jobs; they have said next to nothing about partners and families so we want to change that. It's a Human Right: people are out there doing it. So it's not in a sense they are excluded but they need support not to be abused and not vulnerable so has to be in control.

Globally there are things going on and we need better research and more research and better provision, so please take these messages home with you.

Thank you (Applause).

CHAIR: Thank you Tom, fantastic as ever.

Tom's unfortunately, well, not unfortunately, but he is so popular that he is off to Glasgow to give his presentation this evening, and you can understand that as he is a very forceful presenter.

So, I have 4 kids so that means I have done it at least 4 times, but it's not true because I have twins so only 3 times! A bit of practising as well!

Before Tom leaves, does anybody have any burning or difficult or challenging questions they want to raise. Two questions?

TOM SHAKESPEARE: If you have a burning problem, see a sexual health advisor (Laughter).

CHAIR: Who will be bold?

Yeah there is a hand up over here, my front left, your front right.

(Microphone reference).

Just hold on and put your hand up again, madam. Thank you.

FROM THE FLOOR: Cecilia from 4 houses Hong Kong.

Mr Shakespeare, your last expression about us needing more research and provision, can you talk more about provision? Thank you.

TOM SHAKESPEARE: Well, I think that we need to make sure that our schools are talking to young disabled people about sexual health and sex education. I think too many young disabled people are too ignorant about the birds and bees and we need privacy for people living in residential institutions or sheltered accommodation. We need to make sure that health providers realise that disabled people have sex and babies and are not so surprised. What health providers need to do is communicate clearly and in different formats, and that needs to be in sex as well. If you talk to clinicians they know that sexual health is their business but they don't know they have to make it available to disabled people.

Rape crisis centres: do they support people, women, with disabilities? If there is a women's aid centre, is it available to women's with disabilities to escape from abusive husbands?

All these things should be available to disabled people too. I am not asking for different things: just the same things.

We need peer support to support each other. It's an area of pain and distress. If you are isolated and lonely and if you don't have love in your life, that is painful so we need to address that.

Above all, if we are to meet friends who are lovers we need to have confidence, so it's teaching people self-esteem and how to develop self-esteem and body confidence is really important so they are probably specific disability activities.

CHAIR: Thank you, a good question

(Applause). One more question.

FROM THE FLOOR: I am from the United States. One of the issues that is often wrestled with in your country is about long-term facilities, not just people with disabilities, but those with some level of cognitive

decline. We felt that is more to do with the attitude of the person running the facility more than anything else.

I would like your comments on that.

TOM SHAKESPEARE: You clearly know more than I do. I am absolutely not surprised to hear that. Wrongly, we think that older people are like children and children don't have sex and nor should older people. Yet it's part of life, at all stages of life.

I think we have to be very aware of the risks of abuse but we also need to be aware that sexuality is part of married life and that continues.

Even into later life and the beginning of dementia, people can still consent and are still wanting to be intimate and need the privacy; there should not be the assumption that suddenly it's all stopped because you are an older person or just because you are in a residential institution. I think caring of providers and care home managers has to be really important. It is often a difficult balancing act with protecting people against what they don't want but enabling them to get what they do want.

CHAIR: Thank you, Tom. Can we say thank you to Tom again, because I know he needs to go now. So thank you very much indeed (Applause).

Well, there is nothing like a bit of sex before or after coffee!

It's a great pleasure now to introduce Mike Adams to you. Mike and I met a while ago and we sort of kept in touch.

He has been on a journey in terms of his involvement with user-led organisations and he has looked at the evolution of user-led organisations into a different modus, a different form of operating.

So, Mike, rather than steal your thunder, I will leave it with you.

(Applause)

MIKE ADAMS: Thank you, Stephen.

I have to say I think this is the first time that I have ever followed 20 minutes of sex! (Laughter). I really hope you will bear with me.

We need to change the conversation about disability. We need that conversation to move from one about inequality to one of value.

What better way to change the conversation with over 1000 delegates representing 60 countries, coming together to Congress to come up with an international voice around disability, to create solutions to an international issue.

About a year ago, when I agreed to talk at this Congress, I was Chief Executive of ECDP, an Essex based disabled people's user led organisation, and, we had built, I hope, a good reputation with disabled people who we supported.

We had built a good reputation with Government, as a disability organisation, which represented the views of disabled people and thought creatively about solutions to the issues of today. But we knew that there was a bigger picture that showed that there was an on-going disconnect between disabled people and quite frankly, other parts of society.

We, as a disabled people's organisation, took the bold decision that more of the same was not going to work and is not going to work.

We need to make sure that society thinks and behaves differently.

In a minute I will show you the statistics that show in relation to non-disabled people, things don't seem to have got proportionally much better.

When I go around in my day job I see that the other employers and stakeholders tend to be the usual suspects. And so we need to create a model which changes the way that we, as disabled organisations, and individual disabled people, do business differently.

Purple is different to ECDP, in that along side, it can offer to disabled people/there is also an offer to business. I believe that no group, neither of these groups, can operate and continue to operate in silos, and that we need to come together to create the solutions that will be sustainable for society.

For the month of October, myself and Purple have adorned the cover of Director which is the Institute of Directors' magazine for business leaders. Although it's not quite Vogue, and I still worry the fact that they had to take over 850 photos just to have one, but I think the message we were conveying was pretty straight forward. This is that disability is a business matter. Businesses need to see disabled people as consumers in their own right, and that the bottom line and the commercial advantage of doing this. Business needs to see the advantage of unlocking the employment of disabled people and seeing disabled people as a talent in their own right. And to achieve this disabled people must have the independence choice and control that most in this room have been advocating for years.

The two issues are mutually interdependent.

I want to seek out the key journeys from ECDP to Purple which I hope has resonance with you as individuals and also residents across international kind of borders.

I want to set out some challenges may be for us to take away.

Most of us will be familiar with the statistics, and that the levels of inequality based on a wide range of metrics still exist. We know that this level of inequality is an international issue and not just located within the UK.

As a disabled person I can hand on heart say that the world, for me, feels better and is better but actually inequality exists, and actually in 2016 the world has not moved on as much as it should.

We know that 19% of the UK population have rights under disability legislation. When you talk about 1 in 5 people you can't be talking about and I who that is totally marginal. We know that employment rates between disabled and non-disabled people have remained relatively static over the last few decades and still hover about 30 to 33 percentage points and disabled people are three times likely to have no formal educational qualifications than non-disabled adults.

Interestingly, people may or may not have come across the purple pound, and that is a 202 billion pound market every year where the purchasing power of disabled people, but we know equally that businesses are still in 2016 worried about unintentionally offending disabled people. I did some workshops last summer with a couple of police forces and I thought I was going to talk about how we move the agenda on, and, actually, I had to debunk most of my speech because people were saying, "We are still worried about etiquette. We are still really worried about terminology, and we would rather not have the conversation with disabled people rather than offend them." That is the perception that exists. We ran a survey earlier this year that says 45 per cent of businesses still really worry that, if they were to employ a disabled person, they wouldn't be able to do the job that they were employed to do. Conversely, disabled people tell us that the biggest barrier to employment is the attitudes of employers. I think that is true, up to a point. But there is a need for us as disabled people to take the initiative and to ensure that we have the skills and abilities undertake the world of work as it is in 2016. Purple's vision is to bring disabled people and businesses together for a single purpose, and, in many ways, that purpose is to unleash the power of that purple pound. What do I mean by that? I mean that we should not be worried about thinking around disabled people and disability as a commercial opportunity, and seeing disabled people as consumers; seeing disabled people as a talent pool in their own right.

We have to recognise that businesses are where they are, and that is the starting point for having a conversation with them. We have had so many responses from the Institute of Directors' article that came back and said, "I never thought of disability as a business interest. We need to go away and rethink how we do it."

I think one of the things that gives them comfort is that we don't scold them for all the things they haven't done but say, "Where do you want to go on your journey? How can we help you to do that?"

On the other side, it is about seizing the aspirations of disabled people, to live their lives that they want to live, and provide them with support facilitation, and the opportunity to make it happen. And then taking

those joint outcomes from both business and disabled people, and the lived experience of both, and bringing those together to ensure that the solutions for the future are ones that are sustainable. The model of Purple, therefore, is straightforward. We need to have an offer that works for disabled people in 2016 that builds on the legacies that has been done by disabled people, and continues to be done by disabled people, and the support to disabled people, rooted in the lived experience of disabled people. But, alongside that, we also need to create and develop, and sustain an offer to business, and make sure that disability doesn't remain an exclusive club of disabled people. Because, otherwise, we will never be able to create those opportunities for disabled people in the future. We need to create space for innovation and creativity to define the solutions that work for both. And we believe that you change the conversation by having the conversation. Many of you, certainly if you're in the UK, would have heard of the government's Disability Confident Campaign, and they've recently launched an accreditation scheme for business. I always worry about government initiatives, and the fact that they come out with these initiatives and then expect people just to get on with it. And then worry when it doesn't work or fails, or doesn't connect with the busy lives of businesses. Purple will provide an offer to support businesses to become disability-confident, both in terms of selling products and services and a way of unlocking the disabled talent. And being just more confident around the whole agenda of disability and being able to have the conversation, and what we say conversations without fear. But it is not just the tick-box exercise; it's not just about short-term solutions. It's about building the capacity and the capability of businesses and organisations to understand how disability operates, and to understand how to maximise the opportunities that exist that then support disabled people in their everyday lives, whether they're consumers or employers. And we have created, or we are creating an employment agency for disabled people, because if you absolutely set up expectations, then you need to meet those expectations, both for disabled people who are wanting to enter work, and who are already in work and want career development, and businesses that say, "Well, okay, if we're disability-ready, where are the people in order for us to recruit from?"

So we want to provide some kind of concrete support.

As I said, this is about ensuring an offer to disabled people, and it's a critical part of the equation, is our ongoing relationship with disabled people that drives the futures, both of today and tomorrow. And it's about access to real choice and independence around employing personal assistants, carers; it's around employment opportunities whether you've worked before or not, or whether you're about career development, and it's about that support in work, and Liz, who comes after me, Liz and I have spent a long time in making sure people understand it's not just about getting people into work, but ensuring that they are supported in work, and there's real career progression, and the glass ceilings don't exist. And it is about access to real time information, advice, and guidance. We are living in a digital world, and disabled people

equally need to have solutions that have digital outcomes as well as the more traditional kind of routes of delivery.

So we need to change the conversation. Today, we are publishing our kind of research study on the Purple model and what we think is needed in order to address inequality in our society. In many ways, Tom was talking about relationships. He didn't quite get to talk about marrying, but I just see on my slides I'm not talking about marrying of people, but I'm talking about the marrying of individuals and businesses in a way that perhaps we haven't seen before. So, finally, what do you think the challenges for us in this room today are? That is, how do Rio de Janeiro main, and how do we ensure that we have that value-driven approach to what we have done? But we have a commercial steal, and a commercial understanding as well? How do we ensure that we increase inclusivity, and increase the people in the tent, and don't, by definition, become a more exclusive club? And how do we ensure that working together with business and disabled people we are innovative, and we create products and services? And, for you, personally, a call to action. Think how you can go away today and how you can start to change the conversation, with your existing networks, and think about how you can have conversations with new networks who may not have thought about disability before.

For those of you who have been heavily immersed in disability, how can you change your ways of working to involve more people and be the facilitator in solutions about disability? I would say today, as what I would say, has become part of the Purple conversation. Thank you very much.

[APPLAUSE].

CHAIR: Thank you. Mike. We're going to move on to Liz next, and then we will take you at the end - I saw a couple of hand begun, but thank you very much indeed, Mike, for that interesting journey that you have been on both individually and with your organisation.

Next, again, a pleasure to introduce Liz Sayce, who is the Chief executive of Disability Rights UK which was an organisation not so long ago that was led and run by non-disabled people, but now it's a user-led organisation. So, Liz, over to you.

LIZ SAYCE: Thank you very much. It's an honour to follow Tom and Mike. I just wanted to talk about disabled people creating our own knowledge. Maybe just to start by saying how important it is that we get together like this globally. You may have heard, possibly, that the UK has decided to leave the European Union - whatever you may think about that - but whatever anybody thinks about that, I think we in the disability community need to be absolutely determined to be global in our thinking, to sustain and build relationships. I've put up a picture. One is the United Nations convention on the rights of persons with disabilities. We are currently writing a shadow report - Disability Rights UK is - because the UK will be examined on the committee of the rights on persons with disabilities next year. So we are uncovering a lot of issues that disabled people face around the UK, and we really want to learn from other countries, and,

you know, how you're doing other nations against the consequence. I've put up a colleague of a mine - woman in the wheelchair here - and went to Vienna to talk about good practice, and runs an independent living helpline, and we've been involved in the Paralympics, so really just a plug for global networking. It is so important as we face many similar and indeed different challenges. We describe ourselves at Disability Rights UK as disabled people leading change, and we are working for equal participation for all. So the vast majority of our board members have their own experience of disability across the spectrum. I have had mental health issues, other people may have mobility impairments, autistic spectrum issues, learning impairments, and so on, and most of our staff as well, so we are an organisation that is led and the majority made up of disabled people. We produce a lot of information and advice, all written by and for disabled people. We also run a number of projects led by disabled people, so, for example, we have one called "Get yourself active", and we felt, in the wake of the Paralympics being in London, there was a lot of concern that disabled people weren't being physically active enough. What had been happening was lots of sports organisations had been sort of promoting their activities to disabled people, but nothing had changed, and then the health people were saying, "It's bad for you not to exercise" - sort of shaming people. None of these methods worked. What we are doing, and what really starts working, is just to start with disabled people and what people are interested in. Don't preach at them or sell them things. Just start, when people are planning what support do you need to get up in the morning and go out, and what about physical activity? Are you interested in that? People start saying, "Well, I quite like to go swimming, and I don't know if there will be a hoist or if it will work." It is, "Let's find out", and starting from there. And, actually, more people are getting active doing that. That's just one example. Also, we've got a project running at the moment led by young disabled people, and it's all about improving employment opportunities, and what the young disabled people are doing is influencing local government to use procurement so every time they're spending money, to give some preference to organisations that have a good track record on employing disabled people and who are prepared to take on young disabled people as apprentices, so, imagine if all the money spent by all the governments around the world had a few strings attached, like you're more likely to get the contract if you're good at employing disabled people, that would change things.

We've also got a project - Mike mentioned career development - so we've got a project where this is all about disabled people who are in employment but they want to really progress into middle management, maybe senior management, maybe chief executives, and this is a programme that supports them to do that with a lot of leadership development, mentoring, and all sort of things. If you're interested in that, do ask me. But we also thought, okay, we've got disabled people running the information, and the projects, but what about the knowledge base on which everybody in our nation is thinking about disability? And it struck us that, for every social movement, it's been really important, so to speak, to define our own reality. You

know, if you take the position of women, rather than thinking it is fixed and natural that this is the role that women play, actually, in some countries, that role has changed very dramatically over the last few decades, so it can change. Nelson Mandela said about poverty that poverty is not an accident like slavery or apartheid. It is man-made and can be changed. We are disabled by society, it's not the impairment that restricts us, or not just the impairment, it is actually the barriers we face. And my background in mental health, people started saying, "We're not mad, we're angry." If we're getting frustrated, don't think that's a symptom of mental illness, but the barriers placed in our way, the attitudes, and so on, are deeply problematic. So, it is important that disabled people define our own sense of what the issues are, and that we create knowledge. So, Tom Shakespeare, who is involved in the programme I'm about to talk about, he is chairing our research committee, he said that, in the UK, it was research led by disabled people that documented the discrimination that people face, and that led to the government having to accept that we needed our first anti-discrimination law that's now just over 20 years old. It was also research led by disabled people that said we need more personalised independent living support. Maybe if we want to, to hold the money ourselves and buy that support, and have that choice and control. So, actually, there's - and those research questions weren't being asked by non-disabled researchers in the same way. Non-disabled researchers have a huge role to play, but sometimes disabled people ask different questions. So we have set up a programme called "DRILL", funded by our Big Lottery. The aim is to develop new learning, new knowledge, led by disabled people in partnership with academics and researchers. It's worth £5 million over five years, so it is a reasonably sizeable programme. We launched it in a real spirit of partnership, so it was launched at one of our major TV companies studios - Channel 4 - and we had policy makers, academic researchers, disabled people there, and that's what we wanted all along - working together. Just because we are disabled people leading change, it doesn't mean we are doing things on our own. It means we're doing things in partnership, in this case, a lot with researchers and policy-makers. So what is Drill? It's led by four organisations. My organisation, Disability Rights UK, and Inclusion Scotland who are here today - great to see many people here from Inclusion Scotland here - fantastic. And Disability Wales and Disability Action, Northern Ireland. We've held road shows all around the UK to find out from disabled people what are the big priorities for this research? There is stuff on our website if you're interested. Basically, what people wanted was research to find solutions not just to document what's wrong, to find solutions that will support our independent living in every sense - taking full part in society. We've got big themes which are about participation in social life, in economic life, and in public life, things like being members of parliament, being leaders in different ways or being involved in local communities, so that the research has to be, has to have some leadership by disabled people, and has to be co-produced. Quite often it might be a disabled people's organisation or perhaps a university. And one of the legacies we hope that this will leave is that the universities will learn more about co-production and

how to work with disabled people as partners - not the disabled person being the subject, just the person you interview - but actually being a partner in devising the research at every stage, and equally, the disabled people's organisation will learn more about research, how to get that really crucial evidence about what you're doing; what works, what doesn't work, and what we hope will help them in their development. I'm pleased to say both Mike and Tom are involved in this on some of our committees, so, at every stage of decision-making, disabled people working with academics making the decisions on what gets funded, which research is done, and every stage. So, it is very much disability-led. We will very, very soon be announcing the first set of projects that we are supporting, but I can't tell you that today, but I want to tell you learning from the first round. In the next bit of time, we will have exciting projects, I think, to launch out to the world. But some of the thing we found is firstly, we're really pleased we are reaching out to people who often don't have a voice, so, for example, people living with dementia. It's a relatively new field, people living with dementia actually shaping research. People with mental health difficulties, people with learning difficulties, people who sometimes their mental capacity may be being challenged. So we've got some great proposals in from people who may be don't so often influence the research agenda, and we have found that some of the questions that are posed are different to those maybe more traditionally asked by researchers, so not so much about what interventions work, et cetera, but like, for example, what sort of - Tom mentioned peer support earlier. What kinds of peer support work for us as disabled people, in what circumstances, what needs to be around the peer support to make it work or how do we have supported decision-making and not substitute decision-making. On dementia - I don't know what it's like around the world - but, in Britain, a huge amount of research money goes into how to prevent or cure dementia. But how to live a really good life with dementia, with people living with dementia helping set those research questions? There are some great initiatives in the UK about people with early-stage dementia mentoring others, sharing experience, and so on, rather than just thinking, oh, it is an awful thing to have happened?

I think the other thing we are keen to do - and Mike talked about this - is to change the narrative. We're happy that our four organisations will do a piece of work ourselves, really understanding what is it that disabled people most want to convey to people in the wider society, the wider public business, people working in public services, and then how is that to be done most effectively? Because we kind of felt maybe sometimes we're putting out messages that aren't really the best messages. In the you can, we have had policies of austerity. I think sometimes that's made us really emphasise social protection - you know, have we got enough social security money to live? This is hugely, hugely important, and they are very important messages. But life is more than just getting - just having enough money to eat. Life is about full participation. We may have lost the messages about full participation a little bit in the process, and we don't want to lose it. Similarly, have we sort of talked about discrimination as if somehow we used to think,

we used to have the charity model, and disabled people are the victims of their condition almost. Have we replaced that with victims of discrimination? Maybe, we don't want language of victims at all. They're not victims, the point is to be active participants contributing to society. So we want to explore that, and see how we can have that conversation more effectively.

Finally, just to finish, we would really love to know if there is anybody in the room, either that is working on research led by disabled people, or co-led with disabled people. I know we're not the first people to do this, in terms of there are different search studies that have been done, but we're not aware of other significant programmes like this that are doing that, but we would love to have contacts to learn from others. Also that point about changing the narrative: if anybody is working on that, either practically, in terms of the messaging or using or in terms of research, we would love to know about that, and we would love to keep the dialogue going. Thank you.