

Transcript for Laura Crane conference

(0:00) - Wonderful, thank you very much and thank you for inviting me here today.

So, as Kathy explained I am placed at the centre for research in autism in education - CRAE in London

and the aim of our centre is, we are a research centre, we aim to conduct really high quality scientific research.

But, importantly we really strive with that research to have a very positive impact on the lives of autistic people.

and also we are really really keen to engage with the autistic community and all the autism communities, so families and professionals who work with autistic people, to really shape the way we do the research within our centre; in terms of the questions that we focus on, in terms of the way that we design the studies, and in terms of the ways that we interpret and disseminate them.

(1:00) And this ethos, stems from a piece of the work that was done by the two former directors of our centre, professor Liz Pellicano and professor Tony Charman.

And this was a project called 'A Future Made Together - Shaping Autism Research in the UK'.

And the impetus for this project was because many people had noticed what they deemed to be a translational gap in the research.

So, this is the idea that normal autism research is taking place in the UK and internationally, but actually when you ask autistic people, or their family members, or the professionals working with them 'what impact has this had on your lives?' More often than not, the answer is - fairly little.

So, the future made together project wanted to look at this in a bit more detail. They wanted to look at the landscape of autism research;

(2:00) What kind of research is going on? What's being funded? What's being published?

and they wanted to see if this aligned with what the autism community wanted to see from research.

The other thing that they wanted to do was look at community involvement in research; so the autistic people and their families and the professionals working with them get to hear about the research taking place?, do they get to have discussions with researchers about that work that's going on?, and are they meaningfully involved in shaping that research together?

And the research painted really quite a bleak picture of the state of autism research in the UK.

So the majority of the research tended to focus on the biology of the brain and cognition in autism. And while the autism community though this had value, actually what they wanted was research that more accurately reflected their

(3:00) day-to-day life and have a more immediate impact on them.

When asking about community involvement in research, researchers said that they would do fairly well in this area. So they thought they were disseminating their research in the community quite well, they're engaging in discussions about that work, but, actually when you ask the autism community, they didn't really share that view.

So they often actually had very negative experiences of taking part in research, and also when they did speak to researchers about their work they felt that, actually no matter what they said, unfortunately, it wouldn't have much of an impact on the research taking place.

And the one that all groups did agree on, in this kind of consultation exercise, was the fact that active research partnerships where the autistic community and the research community work together to co-produce or co-create research was a very rare occurrence, indeed.

(4:00) So, one thing that's been suggested as a way to address some of these issues is exploratory research and what I mean by this is quite nicely described in what's known as the Ladder of citizen participation.

So this is taken from Sherry Arnstein and it wasn't actually designed for autism research, or even research at all, but the principles of this still seem to apply.

So the gist of this is that one might argue in autism research generally, autistic people and their allies tend to have not very much power in the research process; the research is about them, but not really with them.

If you move up to the, kind of, middle runs of the ladder, (this) is what seems to be degrees of tokenism, so things like informing people about research and engaging in discussions with them.

And I should just say I don't think that this is a negative thing, I think that has a really important place,

(5:00) and that researcher's need to strive to disseminate their research as well as they can, and to consult with people in a really really genuine and meaningful way.

but what it has been argued is that we should strive to go even beyond that, so we need to move to these kind of degrees of citizen power, where autistic people and researchers are working in partnership to coproduce research.

There's much more power given to the autism community and even in some cases citizen control, where the autistic people are really leading the research in general.

And I really like this definition of participants who are in research as well, because many people say, well – how do you do this? But it's not really a method or a set of methodologies; it's really an attitude that someone has to have, a mind-set, a belief that autistic people do have something to offer this process.

And that's the ethos that we really try to embody with our centre. And it's nice to see that with autism at Manchester as well.

(6:00) So, I am going to talk about participatory research today, but it's not really a 'how to' guide. What I'm looking to do is talk you through a piece of participatory research that I have been involved in, as just one example of one of the many ways that this kind of work can be done.

This is a project that I was very privileged to work on called 'Know Your Normal' and it was a project that was in collaboration with the charity Ambitious About Autism, and Ambitious About Autism have, as a part of their charity, the youth council.

So, this is a group of young autistic people all between the ages of 16-25, who work together on projects and campaigns to try to make life better for other young autistic people.

And the youth council got together, a couple of years ago now,

(7:00) and they were given free rein to focus on whatever they wanted in their project and unanimously, they felt the number one priority for them was mental health.

And this aligns with lots of other priority setting exercises done by other charities such as Autistica, and it was something they were really passionate about producing something on.

So they wanted to set up a campaign and they wanted this to be underpinned by research, but they'd never done research before.

So they approached our centre and said this is what we want to do, can you help us achieve it?

So, myself and Professor Liz Pellicano, who was then our director at CRAE, got together and this picture on the left is the first time we ever met the young people we worked with, so; Jack Welsch (?), Georgia Harper and Fearn Adams from Ambitious About Autism.

We came together in this room and essentially we said to them –

(8:00) what do you want to do, and how can we help you achieve it?

So they spoke about what they wanted to do in their campaign and we spoke to them as well about how research works and the kind of milestones you need to go through, and one of the key things we did was to try to help them take all these ideas that they had and narrow them down into answerable and novel research questions.

So the questions we helped them to develop were as follows:

First of all, how do young autistic people interpret 'normal' mental health? So, on a day-to-day basis what is a good level of wellbeing for these young people?

We then wanted to know, if they were experiencing mental health problems, how does their level of wellbeing, their 'normal' change? Does it change, and if so, how does it change?

We then wanted to find out that if they did have a mental health problem

(9:00) and wanted to seek help for this, what were their experiences of accessing that support?

So those were the questions we jointly decided that we were going to answer through this project, and actually they had many many more research questions than this, and I think a big challenge was trying to narrow it down onto something we could do in the very short time frame that we had.

In terms of who took part in our research the eligibility was the same as that to take part in the ambitious youth council, so it's for young people who are 16-25 years of age, all of whom are on the autistic spectrum and living in England.

And we chose to seek their views through two methods, an online survey in which we had 109 take part, and then some in-depth interviews with the young people to probe some of their experiences in a bit more depth.

(10:00) Now one thing that I want to be really upfront about is that by using these methods, you know, surveys and interviews, we do limit our sample of autistic people to a very specific subgroup on the autistic spectrum.

So, those tended to have good spoken or written language abilities and it's perhaps unsurprising that most of them had a diagnosis of Asperger's syndrome.

So they didn't have a diagnosed intellectual disability and they didn't have a history of verbal language delay.

And we have been criticised for this because many people are going to actually... this cohort of people we are looking at, you know, they're perhaps not a priority in autism.

Perhaps we need to focus on those who have more complex needs, and higher levels of support.

And I take that point and I do think that there is not enough research on that population of autistic people.

(11:00) But, one thing that I find that is really striking from this project was that if you look at the profile of the young people on paper, in terms of their level of education, you know, they all do very well, educationally, in terms of **their aims for (?)** post-secondary education and in terms of their employment status.

These young people are ticking all of the boxes, you know if you're asking for some good outcomes **laws (?)** for a young autistic person, it would be these young people in abundance and yet as I am going on to explain, when you look at their mental health, actually it's really really poor.

And I think that just shows how, you know, this is not a group of young people whose needs we should be overlooking. They need something very different, but yet equally important I would argue.

So, I'll talk you through the kind of key findings, first of all for our survey, and then I'll move on to the interview data.

(12:00) So, our online survey had just over 100 young people take part, and we had 3 key findings in this. So, the first was that the aim to look at what normal mental health baseline levels of wellbeing were amongst this group of young people, and what we found was that on a day-to-day basis when

these young people weren't experiencing mental health problems as such, their levels of wellbeing were fairly low.

So, we gave them a series of statements in a range of different categories and they spoke of how, you know, on a day-to-day basis they tended to report feelings of unhappiness and depression, they felt unable to overcome their difficulties, under strain, worthless, lacking confidence and the list goes on and on and on.

And we gave them a standard measure of quality of life as well, again, just kind of on a day-to-day basis just on how they were feeling and their levels of their quality of life were lower than you would expect for a group of non-autistic young people.

(13:00) and perhaps not surprisingly, our group show quite a high rate of mental health problems as well.

So, around 80% of the young people who took part in our research consist with a lot of other research in this area, experience mental health problems.

And something else which I think is really important to come from this survey was that we found that the young people had, what we refer to as poor mental health literacy.

So, this refers to knowing that you're experiencing a mental health problem.

So, we know that in the typical population sometimes it can be quite hard to know if the symptoms that you're feeling do reflect a mental health problem in need of seeking support.

But, what we found was that this was particularly difficult for our group of young autistic people, and we think that the reason for this is

(14:00) if you are not autistic, you would know you are experiencing a mental health problem because you will develop some symptoms and some features that you wouldn't have had before.

For our young autistic people we found that generally they were struggling in lots of areas, and when they were experiencing mental health problems it wasn't that brand new symptoms were coming up, it was that the things that they were struggling with anyway on a day-to-day basis were just exacerbated.

and what this meant was that it was really difficult for them to know that they were experiencing a mental health problem and they needed to seek support for that, but also it was really difficult for people around them to know that actually, you know, these features or these symptoms are severe enough to actually warrant help and support for them.

So based upon these findings, the young people that we worked with as part of the broader youth council, developed what they called the 'know your normal toolkit'.

15:00 So, this is a series of cards that you can download on the know your normal website and the cards are in a range of different areas of relevance to a person's life such as; staying healthy, interest in hobbies, relationships, self-care and so on...

And on the back of the cards are a series of questions, and the idea is that the young person would use these cards and complete these cards at a time when they were feeling quite good about themselves, when they were happy with their normal.

Then if for at any time a young person would think, well actually something doesn't feel quite right, it feels like something has changed.

They can go back to these cards, and they're not diagnostic, but what it means is that they can map out how they're feeling now, and they can see, you know, this is how I was feeling when I was feeling okay, you know, this is what my normal is

(16:00) and actually things have changed and now it's like this.

So, you know, my normal might not be the same as everyone else's, but something has changed and I am uncomfortable with it.

And they can see that really objectively themselves.

and it also serves as a kind of self-advocacy tools, they could take it to a healthcare professional to map out, you know, this is normal for me, this is what I am happy with, this is how things have changed, and this is why I feel that I need support in this area.

Now, I was hoping to show you a wonderful animation that the young people made to demonstrate how the toolkit works, but unfortunately we don't have sound to be able to play it. But, if you go on Youtube and type in 'know your normal, ambitious about autism' or something similar, or if you go on the know your normal website and it's a very short videos and a lovely illustration of the way that the toolkit can help

(17:00) young autistic people map out what normal is for them.

So that was the results of our survey.

I am going to move on now to the results of our interviews, now throughout the course of this project we were really keen to have our autistic co-researchers contribute as much as possible and one of the things we were really hoping was that they were going to carry out the interviews for the project.

But, actually when we spoke to them this was not actually something that they felt comfortable and confident in doing, and this was for a number of reasons. Firstly, we had a very tight schedule on the project itself and they were worried there would not be enough time for training in interviewing for them to go out and interview their peers about their mental health problems, and they were particularly concerned that this was a very very sensitive issue and they were worried about

(18:00) what would happen if someone disclosed something.

And they didn't know how to cope in that situation.

But, they also were concerned about the fact that they work for the charity or volunteer for the charity, in a position where they support other young autistic people and interact with them, and they were worried that the people that they were to interview would not feel as confident or as

open in talking to them about some of their very sensitive mental health issues, in case they encounter them at one of ambitious about autism events or something like this.

So they asked if I would do the interviews, and I did, but we supported the young people to be able to analyse the interviews themselves and we spoke about how to analyse qualitative data, how to draw the key themes from the data, and they chose all of the quotes that we used to illustrate the themes.

So, we went onto publish this in a report

(19:00) and in an academic journal

and if you read through it, it really is what the young people themselves identify as being important from the data, not something that we thought was key, it really is their voices coming through, which is really key.

The other thing that is really quite incredible about this project was that these interviews were really really hard to carry out, these young people had had such a terrible time with their mental health and it really was just a testament to them that they were willing to sit there and be interviewed about these really difficult experiences just to make things better for other young autistic people.

So, we are enormously grateful that they shared their experiences with us.

But, four key themes came from this data, so the first really echoed what we found

(20:00) in our survey which was that young autistic people struggled to know whether the difficulties they are experiencing are due to autism or due to a co-occurring mental health problem.

And it really just illustrates the challenges young autistic people face, navigating a non-autistic world, and this was illustrated beautifully in one of the interviews we did by instant messenger, so people could take part in the interviews however they felt comfortable whether it was face-to-face, on the phone, via skype, or text message, or email.

And this young person said that they think the reason so many people with autism develop mental health problems is because of the way that they are treated. They go on to say from early childhood, autistic kids are

(21:00) excluded, frowned upon and made to feel unnatural, would constantly be pressured to be more normal, whatever that means.

I think that if somebody who wasn't autistic grew up being excluded, bullied and pressured to be something that they're not, they would very likely develop the same conditions. And I think that's something for us all to reflect on in Autism awareness week.

And another key thing that came from the interviews was stigma, and this was something that came up in every interview, but in very different ways.

Some people were very reluctant to discuss their mental health problems, especially people with less common mental health problems, such as personality disorders or hallucinations or delusions.

Other young people were really reluctant to talk about their autism diagnosis, particularly, girls on the autistic spectrum, who thought that people had a very stereotypical view of what autism was.

And they spoke a lot about, especially this group of young autistic people,

(22:00) they spoke about how they felt that they were seen as not being normal enough to fit in, but not different enough to be normal.

It was a very difficult position that they felt they held in society; it meant that people didn't really understand their need for support as much as other people.

If the young autistic people did identify they were experiencing mental health problems, did overcome the stigma and went onto to talk to people about it, what they reported as well was lots of barriers to accessing an appropriate school.

So they talked about a lack of available services; so very very often they tried to seek help for their mental health, and they were told you've got nothing to support you.

They often went to have a referral to mental health services, there were lots of delays to getting to the top of the waiting list to get seen, but the time they got there they were told 'no, you're autistic, you need to go to autism services'.

(23:00) so, they go back to the bottom of the queue; they'd have their lengthy wait to access the autism service, they'd get there and then be told no, this is a mental health problem.

You know, there is a lack of services to meet the needs of all autistic people with mental health problems, even though we know that that is very very common.

They reported health services weren't tailored to their individual needs.

Very often the young people knew what would and would not work for them, but people had preconceived ideas about what kind of support they would need.

If they chose not to take those up, often there were no other options available to them

and something else that came up quite a lot was how there was some really wonderful services being offered by charities, but often these were very short term, with just a lack of ongoing support that was a real problem.

And disjointed services and poor transitions really came up, so remember these are young people between the ages 16-25,

(24:00) so often when they first encounter mental health services it was through child and adolescent mental health services and they found this to be a really great way to access support because appointments were really regular; they got to develop relationships with the clinicians working with them, it wasn't just for when they were in mental health crisis, there was an acknowledgement that they needed this ongoing support.

But, this one young person put it, you know,” you turn 18 and suddenly services go poof and they disappear”

So, once they did turn 18 our mental health services wouldn't see you on such a regular basis, they would only see you if you were in mental health crisis.

There wasn't as much acknowledgment that people, you know, don't suddenly turn 18 and their support needs go.

You know, they had to make their own appointments, you know, their families weren't allowed to do this on their behalf.

So that support was really really lacking, and this was at a time in their lives when they needed it more than ever, you know, often they are transitioning from

(25:00) school to university or school to the workplace, and there just wasn't enough support to bridge this gap.

And it was really tricky actually when we were writing this because these things aren't easy to address, you know, changing or addressing some of these things would require massive changes to the way our national health service is put together, and you know that that's not going to happen.

But, ultimately, when you kind of bring it down to what the young people are really really asking for, it came down to trusting relationships.

So, they spoke about what they wanted was someone they can trust, someone they can talk to and someone who understand autism - a professional person.

And when they kind of put it like that, is this too much for us to be offering them?

So, on the basis of our findings, the young people

(26:00) wrote a policy report, which you can access from the website, and they came up with three key recommendations in the area, so:

More initiatives to reduce the stigma associated with autism and mental health, greater training for professionals, and more autistic involvement with the design and delivery of services.

And I think it's the autistic involvement that actually transcends all three of these things.

So that's the results of the research.

and I think that one of the really important things about this project was the way, it wasn't unique just what we found, it was the way we co-created this project and what we find is that often researchers don't want to talk about how this is done, and we talk about it a little bit in our report but we really wanted to find a way of sharing this message more widely, and to encourage other people to think about adopting this way of working.

(27:00) So we've created some blog posts, and also some videos where together we kind of outline the process of researching in partnership, looking at some of the ways that work really really well.

And you know, I think in many ways it certainly did, you know, we probably could have done this project by ourselves, but it wouldn't have been anywhere near as good if we didn't have the involvement of these young people, but also challenges along the way and how we overcame those.

So, if you're interested in that part of the process, I will encourage you to take a look at those.

And this is my show off slide now, so we were really really honoured to be recognised for some of this work. So the top left is myself and Georgia collecting an award for public engagement team of the year, from the head of UCL, where I work.

(28:00) On the right here I was invited to meet the princess of Denmark, who is the patron of the Danish autism organisation, to speak about our work and I was really proud of that.

And then Jack trumped me by meeting prince William, who we know has an interest in mental health.

And Jack was able to talk a bit about the know your normal work, so rest assured, as well as sharing with you, you know, it's also been shown with various members of various royal families and the head of UCL.

So, that's the know your normal project, and as I said we found process working together really really beneficial.

But, we know this isn't the norm in autism research, we know that more often than not it is the researchers who decide what they are going to focus their research on, how it's going to be done, how they interpret the data and how they share it

(29:00) So, a little project that we have been working on for the last year or so is that we have been speaking to researchers; those at the early stages of their career, and the senior autism researchers, about their views on this participatory working.

And I should say as well that within this sample of researchers, some of them are autistic themselves as well.

So I certainly, although I often talk about researchers and community members, that's by no means mutually exclusive.

And we're still kind of analysing these data now, so I won't talk about them in too much detail, but one of the key things we found was that there is a kind of growing recognition that this is a useful way of working and it is a way of working that many people are interested in and importantly people with influence like research funders are increasingly advocating this way of working.

30:00 and those who do adopt this position, do talk about how it makes them do better at research, you know, this isn't just a tokenistic way of saying that we are important people, it actually does make a difference to the quality of the research.

But, the issue is that many people aren't really sure what counts as participatory.

You know, how much involvement do people need to have for it to be truly a participatory project and this is really important.

There's been a wonderful paper that's just been published in the journal of autism by the aspire team who are a group of researchers and autistic co-researchers in America.

They're led by Christina Nicolaidis and Dora Raymaker, who co-lead this program of research, and they've developed some guidelines for research community partnerships on how to do this kind of research really well.

And one of the things they caution against

(31:00) Is that many people are using these terms to describe their research but actually there is no power that goes to the participants.

And they gave one example of a person who entered into a research project that was built as participatory in nature, but actually when they got there, realised that actually they'd be consulted about some aspects but it wouldn't actually change necessarily much of the project.

And this person said, you know, if my expectations were set out clearly in the first place- fine, but we need to be very careful that we don't overstate what we are doing.

And I think one of the other key things that came out is that researchers do need a lot of support in this area to know how to do it properly.

They spoke about a lot of barriers and a lot of challenges in relation to this way of working, and I'm certainly encountered a lot in the participatory projects that I've done,

(32:00) university financial systems being one in particular academic nightmare.

But, ultimately I think we've got to remember that actually, it's not just participatory research in autism that's hard, you know, all research is hard, and all research has its challenges, and we have to think really creatively about ways to overcome them, and that goes for working with the autistic community in participatory work as well.

So, I think yes there might be barriers, there might be challenges, it might be a new way of working, but we can't just discount it because of that, we need to have this mentality that the autistic community has something really important to offer.

And we will try our very hardest to, you know, make sure that that's reflected in our research.

And in terms of how to achieve this, our data show that it comes down to a couple of things really, firstly really good quality mentoring. So, this I'd say is not just for people in the early stages in their career

(33:00) but even for more senior researchers, you know.

If I'm going to do a research project looking at some aspect of genetics that I know nothing about, you know, I wouldn't go at it alone, I'd get someone in who knows about that area to collaborate with me, and I think that's the kind of mind-set that we need when we think about participatory work, you know.

There's so many great examples of research centres working in this way, with expertise that are drawn on for these projects,

So I do think we need to work together a lot more to share examples of best practice,

And I think the second thing is really to make sure we work really hard to develop more trusting relationships with our autistic co-researchers.

There's a lot of distrust about research in the autistic community, and I think it might take a long while to build a lot of those bridges, but I think it's really important that we keep on trying

(34:00) and many of the people in our research spoke about just needing somewhere to start, some kind of resource.

One thing we have created is part of the shaping autism research project that was led by Professor Liz Pellicano, looking at how we can make autism research in the UK more participatory in nature.

It was originally conceived as a resource for early career researchers, but actually I think that it's a resource for anyone.

It's free to download from the website.

It just gives you a few tips on best practice in terms of sharing your research, in terms of engaging in collaborations and consultations with people and also co-producing research.

One final thing I was going to mention; I've spoken a lot about co-production of research and co-creation of research, but actually, I think you also have some fundamental issues in autism research in the UK.

And they were really highlighting the future made to together report that I mentioned

(35:00) at the start which was how the autistic community often have negative experiences of taking part in the research.

So, not just you know, leading the research agenda and co-creating the knowledge, but actually just coming into research centres to participate in research.

So a project that we're starting very soon now is called the research passport.

It was an idea from one of our autistic co-researchers at CRAE(?).

It's an idea that came about from other passports used in healthcare and justice as a way of autistic people and families to convey needs to researchers in advance of coming to take part in research, to make sure that the researchers are aware of people's needs and they can actually do something to address them.

So, we will be starting work on that project next year, in collaboration with the charity Autistica,

(36:00) so hopefully not just influencing the way that research is coproduced but also making the experience of research fundamentally better for autistic people as well.

Kathy was waving her hands to tell me to stop, so I will.

But before I go, I just want to say thank you to Fearne, Jack and Georgia who coproduced the know your project , it was an absolute privilege and pleasure to work with them.

And Hannah, who was interviewing people about their experiences in participatory research, and to my mentor Liz Pellicano, who has worked with me on all of the projects I have spoken about today and who is an incredible researcher, who really, for me when I was an early researcher , you know really fostered that ethos for participation which I think is so crucial, and finally thank you all very very much for listening.