Hopkins Hour Questions and Answers
20 May 2020

The Dignity Project

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Panel members that will be answering questions via audio only:
Elizabeth Kendall, THC Executive Director
Kelsey Chapman, Dignity Project Researcher
Angel Dixon, Dignity Project Researcher

Question and Answers:

Question one:
It is essential that dignity be defined from the perspective of the citizens themselves and provide services that meets their needs, you mentioned that the definition will be formulated from the citizen who is disabled from their perspective. Will there be inclusion of culturally and linguistically diverse groups including first people as dignity can be bound within one's culture tradition and values and may not fit a common description of what I'm doing fine means.

Answer:
Kelsey response: I might just start us off if that's ok with my fellow panel members. This is a great question and it's something we are looking at, we are looking at a number of intersectionality's for people with disability So it's not just about the disability culture, education, gender as you said culturally and linguistically diverse groups. Immigration is also an issue that plays into this, being viewed as a citizen or as someone who is not a citizen of a country, can also impact on how your human rights and dignity are delivered. It's something we're definitely looking at, intersectionality is with different disabilities, economic, background and location. I know that this is particularly important for first peoples and some cultures where your dignity is tied directly to community and religion, caring for your elder, and so it is something we're examining. I would say it's not the primary aim of this pilot, although we will be looking into it, but it is certainly something we are looking to pursue and some of our future research and my PhD specifically, which is in a little bit of a different vein does examine some of those intersectionality's.

Angel response: I would probably just say that the beauty of the community hub as well is that we are sending this out into social media land and into a lot of other networks. Anyone

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who identifies from any identity or group can become a member of the community hub and we actually hope and encourage people from as many diverse backgrounds as possible because we need diverse perspectives to come and share their stories and not just share the specifics around what they feel we want around what dignity is or what their experiences have been, whether they're positive or negative. But also share some of those cultural perspectives and some of those individual barriers that they feel they experience, so that we can bring that into the data that we collect now outcomes.

Elizabeth response: Another issue that we discussed at length is how we make the platform really accessible in a range of different ways for different cultures and that might evolve into very different platforms in future, so that sort of information we're looking for as well.

Question two:
I'm interested in hearing about the response from consumers to the Hub.

Answer:
Kelsey response: We are approaching close to 40 members of the Community Hub now. We have been live I think for about 3 weeks, that might be 3 weeks today actually. So far the response has been really positive. You know we acknowledge that there are some accessibility limitations of a SharePoint platform, which is what we have built, but we're doing our best to overcome whatever limitations there maybe. So far we haven't had any complaints and It's been really positive experience. We're just looking forward to really getting into the nitty gritty of it and interacting more on a regular basis with our consumers.

Question three:
How can people join the Community Hub?

Answer:
Kelsey response: We actually have that on our last slide. There's little link that people can click on you can also visit The Hopkins Center website. We have a Dignity Project page you can click on the community hub button and it will take you there. There is an intake form, it's just a quick couple of questions that asks for your email and what disability you identify with if you do at all, and from there we just approve your access. So it's a fairly streamlined process.

The Dignity Project website: http://www.hopkinscentre.edu.au/the-dignity-project

Join the Community Hub

Complete the Dignity Project Survey

Question four:
How did the dignity project find citizen scientists to partner in the research?

Answer:
Elizabeth response: We are really fortunate in The Hopkins Center that we've always had an orientation about building research capacity in people who are most affected by our research, so we already had quite a process underway with our ambassadors council and those that you've had some interactions with the ambassadors council would know that

those people have lived experience of disability and developing research skills and talents in order to promote research as a reasonable activity for all people with disabilities, too many people with disabilities to engage in future. So finding people with disability who had research interests was not that hard at all. But I think one of the most important things to think about was that citizen science is very closely aligned to advocacy and community activism, so it was also really important to find people who have that passion to bring about change in society. So that's how I connected with Angel and I think that was probably the most important move that we made, was connecting with Angel, who is not as she says, not a researcher, she actually has a very scientific way of thinking about things and is developing that even more. But I think more importantly, she had that sense of activism and the drive about using knowledge in a way that makes change in society. I think that's what we were looking for most of all.

Kelsey response: I think for people who are interested in finding a citizen scientist to partner with, the community hub is a great place for you to start. So if you have a particular project that you would like us to connect you with someone who might be interested in working with you on research, just again please get in touch with us and that's something we are hoping to build capacity for moving forward, were we will have our hope is a project directory within the community hub where individual research projects can make a listing and engage with citizen scientists that way. So that's something we are looking to build on in the future.

Question five:
How will l the dignity project report its data?

Answer:
Kelsey response: Reporting is important. At the moment we are funded by the Office for the Queensland Chief Scientist, so we will be doing our reporting to them. We will also be reporting back to community hub members through that platform and ultimately our hope is to develop a report that we can circulate more broadly.

Question six:
Is the dignity project inclusive of children with disability and their families viewpoints?

Answer:
Angel response: It certainly is, the reason that the platform for now or maybe for a while, there maybe another section or in a later stage of research where we have support networks, but the reason that we have personal lived experience and people with disability or people who identifies people with disability or qualify for services, is because we want that that unique lived experience from a personal perspective, that doesn't preclude parents or support workers from assisting a person who requires the support, to participate in the hub from being involved in answering our forum questions and being involved in the hub. So certainly, if there is a kid out there who was really interested in sharing their experiences, we want that, if mom and dad are their support to get them there to answering those questions, come along and do it, totally.

Elizabeth response: It is really important that we evolve overtime. So I think someone's also made the point in the questions, that it's important to hear from citizen scientists who don't have research and activism backgrounds, and that's exactly right. One of the roles that

Angel is taking, is to bring other consumers into this system and provide the skills to become citizen scientists themselves. Now that might mean actually asking different questions to what we're currently driving, so we currently driving a couple of questions about dignity and in certain contexts, but as this progresses, there will be opportunities for citizens themselves who are engaging with the platform to be asking you questions and driving new research projects that perhaps don't even involve us. So I think so there's a couple of things there, one is that the platform can be used in future to answer very specific questions for a very specific audiences and in that way our members will be contributing to change in that area and ensuring that that area has good information on which to base decisions. But it will also become a place where we can start exploring our own questions of importance and then feeding that to the right places as we progress. Another point that I just wanted to add, is that it's we have an orientation that people who are doing this research are not unpaid labor for anyone. So while we value the concept of citizen science and that people can participate in science, it's not about being free labor. I think in the disability world, we've had such a long tradition of people sitting on panels and avoid you know contributing to major decisions and not being paid for that when everyone else on the committee is. So we also are committed to looking at ways of making this a sustainable action for the future.

Question seven:
Why is accessible communication so important?

Answer:
Angel response:
It's a great question. It's a loaded question, because there's a lot of things in included in what accessible communication is, both from how you communicate things, how we provide our reporting and outcomes, whether that's in easy English and all those kinds of things for people that require it, or as simple as accessorily on a platform, it can extend to inclusive framing and the language that we use when we're discussing disability and making sure that those things are up to date with contemporary values and concepts. But it can also be on the flip side, so it is how a person with lived experience wants to consume. There's just a lot of things in that question. But the importance of all of those things, is that we are making sure that everyone can participate and feel comfortable participating, that's the important thing, because there are a lot of people with disability who just push through, because it's almost close enough is good enough, with the things that we have at the moment. For us, close enough isn't good enough on this his project. People with disability need to feel comfortable in sharing their stories with us, so that we can collect the best data and so that we can make better solutions at the end of this, solutions that aren't retrofits, that aren't being built on problematic systems that we have had in the past, they are new and innovative things that come from the wants and needs of people right now. So that's the real importance of it. I am happy to catch up and talk more about the concept.

Question eight:
Will there be coaching for citizens to become researchers within the research team?

Answer:
Kelsey response: Yes, so far that has been one of our priorities as part of our grant. That is, Angel is doing some training. Now obviously due to the COVID19 pandemic, some of our

initial plans have changed a little bit around that, but i know that this week she did a systematic literature review course and there's as a couple of other ones that her and I are doing together. Longer term, we do work with Health Consumers Queensland and they have allowed us to put up a number of their consumer engagement resources in our resource library section. So those are available to people to peruse at their own discretion and we're hoping to develop more of those resources, as we go on in order to give people access to more capacity building and training.

Question nine:
Can you share the process for designing the community hub to promote an accessible platform, particular interest for participants with cognitive and communication disabilities?

Answer:
Kelsey response: It's been quite a process. We've been working on this platform since August. We have partnered with the business enablement team at Griffith, particularly a fellow named Marcus, who has been very helpful to us in designing the SharePoint. I think, like we said, there are some limitations in SharePoint, that we cannot address all matters of accessible communication and accessible participation, but at the moment we have done the best that we can. We did have the SharePoint platform tested by Scott Holier who is from the Center of Accessibility, and you know there was mixed reviews on the platform and there are limitations that we acknowledge, due to the Microsoft platform. I think long term, our plan is to overcome those issues. Again as this is just a pilot, we were just sort of seeing what we could get done. There is a screen reader functionality within the platform itself and it is compatible with the vast majority of assistive technologies as far as we have been informed and as far as Scott's undertaken. But it is an ongoing iterative process for us, absolutely.

Angel response: I think the challenge of this being a pilot, is that unfortunately we are working with the systems that haven't quite been changed yet. So we yeah, we will be working to innovate on our platform moving forward. As far as people with intellectual impairment and people that require different styles of communication, we certainly have access to those things for people who require them. Within the hub if you make it known that you require a different form of communication or a different form of document, let us know, and that's something that we have access to, and we can provide.

Question ten: What are your recommended processes around consumers who want to remain anonymous due to service vulnerability but have lived experiences of abuse and mistrust and want to voice.

Answer:
Kelsey response: Just an initial comment around that, one of the great things about the community hub in this instance, you do need your email to register, but beyond that your participation is anonymous, so all of our forums and all of your interaction within the platform, can be done in an anonymous way. So that is a great place to start. We recognize again, it is just a starting place, but we're building through some functionality around commenting and posting in other ways besides just the forum where you can remain anonymous.

Elizabeth response: Only to add, that it is such an important point, that we need to be able to provide that privacy as well as publicity. Some people want extreme publicity as well and that's something that we should be able to adapt to. But those are the voices, the very voices, that you're talking about, are the ones that need to be collected and shared. I do hope that we get those voices as well and you know if there are things that people think we can do to encourage people who wouldn't otherwise speak to share this story that would be really good advice for us.

Kelsey response: I think in some of the data that we have already seen come through the survey, some of those experiences of abuse and mistrust have already been shared and that is obviously an anonymous survey. People can attribute their name and contact details if they want, but they also don't have too. So far we have had some stories come me through around those experiences and we are hoping that people feel safe to continue sharing with us in that way.