

Diversity and Making: A Podcast and Video Series
A Collaboration of Purdue Libraries and School of Information Studies and Purdue Asian American and Asian Resource and Cultural Center (AAARCC)

Episode 2: Makers Making Assistive Devices (Release Date: October 21, 2020)

KM: Kristina Mok PS: Pamela Sari SH: Sarah Huber

KM:

So with the open source model of makers, making change, you're giving people disabilities a greater say in the devices that they're using. So rather than forcing a user to adapt to a device that doesn't quite work for them, you can adapt the device to suit the user's needs.

PS:

Hello, everyone. Welcome to the second episode of Diversity and Making, A Podcast and video series. Diversity and Making is a collaboration between Purdue Asian American and Asian Resource and Cultural Center, otherwise known as the AAARCC and Purdue Libraries and School of Information Studies. I'm Pam Sari, director of the AAARCC -

SH:

And I'm Sarah Huber, Assistant Professor, and I run the Maker programming for the libraries.

PS:

In this program, we will engage the diversity of the Maker communities through conversations with our guest speakers and making projects for our Purdue community. Our guest today is Kristina Mok, operations lead and industrial designer at Makers Making Change. Makers Making Change envisions economic and social inclusiveness for all people with disabilities. It leverages the capacity of community based Makers, disability professionals, and volunteers to develop and deliver affordable open source assistive technologies. Thank you for joining us today, Kristina.

KM:

Thanks for having me here.

PS:

So reading about you, one thing that truly impresses me is your desire to solve challenges faced by people with disabilities and your belief that design should be built around the users and not the other way around. So what was your pathway into making and what led you to work specifically with assistive devices to help people with disabilities?

KM:

Well, I personally have some friends and family that have disabilities. And growing up, I always noticed little things here and there around the health and in public spaces that I thought could be tweaked just a little bit so that's easier for them to use, you know, things like one handed packaging or a larger gripping surface for utensils. And that was something that I had in the back of my mind when I went to university for industrial design and just really focusing my design projects and my graduation thesis on designing for and with people with disabilities. And so when I found out about Neil Squire Society and the work they do, you know, I took the opportunity to join the organization and I've been here for four years now.

SH:

When you say join, do you mean you started out volunteering? Or what way were you joining?

KM:

Oh, I actually started as an intern. And that was at the beginning of the program that I'm part of, the Makers Making Change program. And so I started as a volunteer and here I am helping out, you know, with events and just with the program as the operations lead and industrial designer.

SH:

Cool. Thanks. So can you tell us about the Neil Squire Society and how Makers Making Change grew out of it?

KM:

Yeah, so Neil Squire Society is a Canadian nonprofit that empowers people with disabilities through technology. And we've been around for 36 years now this year. And it started as the organization was created after Neil Squire, who was a student at the University of Victoria, here in British Columbia. He got in a car accident that left him tetraplegic, so paralyzed from the neck down and dependent on a ventilator. And his cousin, Bill Cameron, built a sip and puff machine so that Neil could communicate with the world. And so through that machine his quality of life improved. And, you know, at that time, nothing like that really existed. And so that really, really helped Neil, but sadly, a few years later, he passed away. But seeing the impact that technology had on his life, the Neil Squire Society was formed to help Canadians with disabilities. And 36 years later, we have offices across Canada with programs that are helping people gain skills, find the right assistant device for them, and find employment. And the program that I'm part of is called Maker's Making Change. And we connect people with disabilities to volunteer Makers who can build assistive technology for them. And it can be really simple things like 3D printing a bottle opener or building more complex devices, similar to Neil's device. And the one that I'm referring to is called the lip-sync and it basically allows someone with no arm movement to control their computers or their laptops independently. On our website, makersmakingchange.com, we have an online library of open source designs. And basically people can look through and request directly on the device page for a volunteer to build it for them and they can collaborate online. And all the requester has to do is just cover the cost of materials. So when you're comparing it to a commercial device, it's only a fraction of the cost, which helps a lot because there's sometimes a lot of financial barriers to accessing

assistive technology.

SH:

Can you explain - you had said that at the time Neil got that assistive device made for him, there wasn't anything like it. And this was about 36 years ago. Are you saying there wasn't that type of technology with assistive devices or the structure of working with an organization to develop assistive technology?

KM:

So for someone with that high level of injury that Neil had, there wasn't a lot of technology getting them back to, you know, their previous communication modes with, you know, people, their friends and family. They were kind of just expected to kind of not do anything, which is really sad when you think about it. And so his cousin was an engineer and working with occupational therapists and other engineers, they were able to develop that sip and puff device so that you can communicate via Morse code with the world, really. And so he was able to talk to his friends and his family, and that was just a really big game changer in terms of assistive technology back then.

SH:

I mean, that is really recent, so.

PS:

Right. And I think what amazes me is it starts with someone, right? A cousin who cared and then started thinking about, okay, what can I do to help? And then it involved other people around them. So how did that, I guess method of caring - how was that translated into Makers Making Change, where you involve a community of Makers to assist people with disabilities? How did that vision kind of translate?

KM:

Well, around 2015, 2016, we were challenged to take, you know, a similar device like, you know, the sip and puff device that Neil used and make it open source so that people who need that type of technology can access it easily. And so we actually got a Google or grant from them to take that into an open source model with the engineers. We were able to make it a Maker friendly device. So doing a lot of research into, you know, sip and puff devices in general. And what came out of it was a device instead of paying \$1500 for a commercial device, it could be built for \$200 with parts from local electronic shops and hardwares from, you know, the hardware store like Home Depot, for example. And so that device is the lip-sync and that basically started Makers Making Change and led into this online library where people can contribute their own designs, but also the R&D, you know, engineers on our team can also build it and just make it open source for everyone to access.

SH:

It is a perfect fit. Just to your point, Pam, about making is about community and helping and making it as affordable as possible. I think that is a good lead-in to our question about volunteers. Can you tell us about the culture of your volunteer Makers? What does it take to become a volunteer and what does their relationship with clients look like?

KM:

So when a person with a disability is browsing through our online library of open source designs, they can directly request a Maker to build it, and that request is actually pushed through our forum where our makers can reply to that and be like, "Oh, I can take on that

project." And so the requester and the maker, they're just collaborating online and they can also modify the design to suit their needs. And so, for example, if a parent of a young child is requesting a 3D printed writing aid for them, the maker can go into a CAD program and scale the design up and down. So that it fits their hand better, or even add text to it, things like that. So it's a pretty cool collaboration in that way. And what's neat about our volunteering is that the requester doesn't have to be in the same area as the person who's volunteering. And so you can have someone in Vancouver request for a device and have someone in New York that's fulfilling it. So it's a really cool way of just volunteering beyond, you know, your geographical community. So if people are interested in volunteering, they could also go to our website and just sign up as a Maker volunteer and have a look through our forum and our site. There are a lot of different ways for a Maker to engage with our program. On our website, we also have the ability to suggest device ideas and again, through our forum, they can collaborate with the Maker to turn that idea into reality and then once that device is built, that could be added to our library so that people with similar needs can benefit from that. It's just this whole collaborative community that's online.

SH:

I noticed that about the forum is that people could give feedback. So if I submit a design, other makers, other people can say, did you try this or does this work? And I like that community part of it too.

PS:

I have a followup question for you. Obviously the design - you mentioned earlier that, you know, reducing costs is a big goal right off Makers Making Change. So in this case, who pays for the - obviously the Makers are volunteering, but who pays for the cost and what would you say about the cause of these projects?

KM:

So in this scenario, the requester would cover the cost of the materials and because everything is open source, there's, you know, the instruction files included and also the bill of material. And so you can see where you're getting the parts from, and you can also, you know, just check the prices there. So it's, I think it's a pretty transparent process. And of course, before, you know, actually building it, the requester and the maker kind of come to an agreement about, okay, this is kind of the approach that you're going with. Is this sort of the path that we're going down with, you know, the modification and just making sure that, you know, there's no surprises there.

SH:

And one last follow up question to that. So I didn't know that - I think that's interesting. Makers can be anywhere, which makes sense. But do you also have an in house maker lab that people can do some work on? Because just looking from your website, it looks like you have a pretty elaborate space, but maybe I don't know.

KM:

Yeah. So we have engineers on the team and I'm the only industrial designer on the team. So it's a pretty small group of R&D people, but again, we rely on, you know, occupational therapists to let us know what works for people with disabilities. We have people that are helping us along the way, you know, through our forum. And there's a really big community out there online that is really focused on open source assistive technology. And it's a really collaborative and very supportive community where we're like, "Hey, did you see this new technology come out?" Or like, "Oh, hey, did you see this new part that can make this device cheaper to build?" things like that.

SH:

But I could go in and work in your labs. People can - you have a Maker lab that people can try to build stuff in?

KM:

Um, we don't have one that's publicly accessed. So that, those -

SH:

That's just for R&D?

KM:

Yeah, that's just for R&D, but we also engage with local makerspaces. So here in Vancouver, we work with the Vancouver Hackspace, so that, you know, a lot of their members are also volunteers with us as well.

PS:

We're interested in how Makers Making Change responded to COVID-19. Right. So what PPE designs and processes are in development as a result of COVID-19. And also I'm wondering if you can tell us a little bit about how you approach your build-a-thon events that you have done successfully right in the past?

KM:

So we used to host a lot of in person events, and now we've transitioned that to an online system where our MMC staff or our volunteer chapter leaders are walking volunteers through building a device from beginning to end over Zoom. So all of that is done remotely now. And then we have an online calendar where people can see when we're hosting those events and they can join that as well. We have some PPE designs in our library. But we we've also put together sort of a document sort of a "best practices" document that sort of pulls together a lot of information that's out there and just providing tips for makers who are building PPE and approaching it from, you know, a safe way where it's, you know, taking care of your sanitization sterilization of the device, if they're going to be sending it to the hospital or to people who are going to be using it. One of the projects that's in our library is a sip and puff adapter - a mask that is adapted for sip and puff users. And that was actually hosted by one of our volunteer chapters. And it was attended again, virtually online and people were able to follow along and sort of replicate that for either, you know, someone they know, or for people in their organization that could use it.

PS:

So what happens, Kristina? I'm just curious. If a Maker does not have the tools needed for that particular job - does your organization provide it for them or they have to go to a different Maker or what happens if they maybe got stuck in the way? Right. And then they got stuck in the middle of the project. And then, "Oh, I just realized I don't have this," or "I need this particular tool." How does your organization help?

KM:

Well, we can always support them, either by directing them to a local maker-space, that's close to them or a, you know, a place that has those tools. So we find that a lot of libraries, public libraries have 3D printers and a lot of schools also have 3D printers. So say for example, if someone who's really, really skilled at CAD can modify the device, but there's no way to print them so they can go to, you know, a space and we can help them or link them to a local chapter to direct them to a place where they can 3D print. Another thing with volunteering is that the Maker doesn't have to volunteer alone. They could work with other Makers too, right? So you can have that CAD person work with someone who has a 3D printer at home and they collaborate and just get the device to the person who's requesting it. And so it doesn't have to be a solo endeavor for them.

SH:

Do you have requests all over the world? Or do you find you get requests from a certain region or country?

KM:

We get a lot of requests from Canada and the US mainly. Sometimes we have requests from different parts of the world. We have a collaboration with a company called print labs in the UK to develop a curriculum. And so a lot of these assisted technology groups are kind of just spread out all over the world. And again, everything is online and open source so that we can feed off of each other's information and just kind of improve everything.

SH:

We're sure you have many, but do you have a story about a person requesting a device and the volunteer making it that is especially close to your heart that you could share with us?

KM:

Our program mainly operates in Canada in the US - mainly in Canada, just cause we're a Canadian organization. But earlier this year, we had a gentleman who reached out to us from the Philippines. He is from a remote town and he is a quadriplegic and really depends on his laptop, but he doesn't really have a way to control it independently. And so he came across our lip-sync device and he really wanted to try it out. And prior to that, we had a lip sync build event. So we were actually able to send him a device and he got back to us later saying that he was able to use his laptop independently. And it's always just really good to hear that.

SH:

Yeah, that's cool. Thanks.

PS:

So, Kristina, Makers Making Change mentions that many of the projects reflect the intersection of industrial design, equity, and open access. Why is this intersection important in the mission and how do you think a university like Purdue can benefit from thinking about these intersections?

KM:

Well, our mission is to make assistive technology more accessible and to remove some of those barriers that they might encounter when they're looking for a device that works for them. Sometimes with assistive technology, one size does not fit all. You know, disability can vary from one person to the next, and then the commercial, the existing commercial market for assistive technology is pretty small right now. And so you're not getting a lot, you're not getting a huge variety of choices. So with the open source model of Makers Making Change, you're giving people disabilities a greater say in the devices that they're using. So rather than forcing a user to adapt to a device that doesn't quite work for them, you can adapt the device to suit the user's needs. And so we have a goal to bring this to people with disabilities. We want to establish a Makers Making Change community chapter in every province, state, and territory in Canada and the US by 2030. So far, we have about 30 chapters, none in Indiana right now, but we have these running - we have these awesome leaders who are just running these chapters out of their makerspaces, out of their schools and their disability organizations. And they're just really awesome advocates for people with disabilities in their community.

SH:

Can you tell us a little bit about the chapter? If Purdue students are interested in starting a Makers Making Change chapter in Indiana, can you tell us what it means to have a chapter and how they

would go about starting it?

KM:

So with the volunteer chapter, you're kind of like the connection between the people with disability side and the volunteer side. And there are a lot of different things that you can do with it. And it'll really depend on what the leader's expertise are and what the member's expertise are. So you can be focusing on just fulfilling requests online and helping people turn ideas into reality. You can host build events and talk to disability organizations and really advocate for open source devices for people with disabilities. To start a chapter, you can go to our website makersmakingchange.com. And at the very top in the resources tab, you can see a dropdown menu for volunteering chapters, and you can see more information about that and fill in an application. And then our community community manager can reach out to you to help you start your chapter.

PS:

So, okay. Listeners, our project for this episode is to make a raindrop switch. Kristina, can you tell us a little bit about that?

KM:

Yeah, so the raindrop switch is one of the devices that you'll find in our library, and it's a switch that's used by people with severe low motor limitations, or maybe in a power wheelchair. And it's an alternative input for them to control a device, whether that's a phone, computer, a toy or a gaming console. So the switch is about the size of a quarter and it has a cord running out of it with a mono plug at the very end. And you insert the plug into the device that you're controlling and you just press out the switch to perform some sort of action. And there's a lot of different uses for a switch like this. So for example, for a gamer with disability the traditional handheld controller may be hard to use if they have some sort of finger dexterity issues. So about two years ago, Microsoft released the Xbox adaptive controller and that basically allows gamers with disabilities to use switches instead of pressing directly on the control. And so now people can use 4 external switches for the A, B, X, Y buttons and put it by their wheelchair arm rest or on a tray, just bring it closer to them. But the issue with switches is that they're super expensive. They're about \$80 and up each. And so when you're talking about those four switches, that's \$320 right there. So with the raindrop switch, the cost of materials is less than \$10 per switch. It's got two, 3D printed components and two electronic components, and it's about 15 minutes to assemble. So it's a very approachable project for volunteers, and it's a very useful device for those that depend on access switches.

SH:

Thank you, Kristina, for joining us today for this conversation. It's been very interesting. We've enjoyed hearing about your path into making, working with assistive devices for people with disabilities, the story of Neil Squire and how a Makers Making Change came out of that. All the important work your organization is doing to connect people with Makers to make assisted devices. And then of course all the open source information you're making available. And I really hope our students look into this opportunity to have a chapter here in Indiana. I think it's a great opportunity and a lot of important work could come out of it. So thank you again. And finally, we do have 30 free materials kits that students can come and pick up - it's for first serve, first come first serve to make a raindrop switch. So that will be available October 26 in the Wilmeth Active Learning Center first floor by the reference desk. And if you can't make it and we have some left over, we'll have them on the second floor reference desk in the Wilmeth Active Learning Center until they're gone. All right, we will be dropping another pod in November. So stay tuned. We'll get that information to you soon. And special thanks to Drew Alkire for our podcast music, keep on making!

PS:

And Boiler up!