**TRANSCRIPT (not exact wording via manual live captioning)**

**Event Description:**

**Kramer Hoeflich (I-Lead chair) and Paula Tesoriero (Disability Rights Commissioner) co-hosting a zoom panel discussion with members of the I-Lead team on Young Disabled People in life in Lockdown COVID19.**

**Tuesday 23 June 2020**

Kramer: Kia orana from Kramer, chair for I-Lead joined by Paula Tesoriero, Disability Rights Commissioner as co-host.

Paula's role is a statutory role under Human Rights Act, to protect the rights of disabled people, to shine the light on issues affecting us in New Zealand.

Paula: I saw a lot during those weeks of lockdown. Tough time for many. Really looking forward to tonight with awesome panelists.

Kramer: I-Lead is a youth collective who make sure young people with disability have a voice. Purpose of this is to hear voices of young people during lockdown.

Kramer: Introducing NZSL interpreters Stephanie and Melody. Their videos can be pinned if needed.

Kramer: Big welcome to everyone joining us.

Josh: Hi guys, my name is Josh Fuimaono - digital coordinator for YesDisability and I-Lead, social media, newsletters and more.

Kathleen: I'm more of supporter - I do personal experiences, need anything about I-Lead ask me!

Tamara: I'm Tamara Grant, founder of Xabilities - disabled parents committee at YesDisability. I'm an ambassador of the invisible disability side of things.

Kim: Hi guys I'm Kim and I'm a part of the Yes disability committee (loses audio)

Kramer: Kim was former disability rep at MIT. Has started at ACC recently. Completed Diploma in Business Management.

Kramer: Asking panellists "How would you describe the lockdown?"

Josh: It went in stages - first and second week really relaxing, nice to be at home, a lot of video games, after mid-week two it started getting really boring and then around then me and flatmate went shopping.

Kramer: I found lockdown actually really good. I work so I was able to actually work from home and still keep myself busy.

Josh: Really weird having to stand there - realised couldn't do what I usually do. More steps in process of getting to shops, doing what I need and getting back out. Lucky went with flatmate. Ended up pretty good. Flatmate has a health condition - we had to keep ourselves super safe. Pretty much casual for me, chilling, then tiresome and boring and wanted to communicate with other people.

Kathleen: When lockdown started my grandma passed away. We weren't allowed to do a funeral. Last weekend we did a funeral, but we had to wait all of quarantine. Same as Josh with shopping. I wasn't allowed to go with my partner cos only one person per household, but I have to have someone with me. That was pretty hard to get through, hours in line, I had to take my chair, my wheelchair in line, lug my trolley, it didn't make sense. I kind of liked the bubble. It is a bit hard, but we are getting through it.

Paula: Kathleen, sorry about your grandma. The experience you had about going shopping I've heard from a lot of people. What are your thoughts on going with someone?

Kathleen: You got a dirty look. One time we waited in line, trying to get in, security guard would only let one of us in and I had to go in on my own. It didn't make any sense, now in level 1 back to normal. Pretty stressful to wait in line for weekly food shopping. I thought what if I show total mobility card - I have arthritis, you can't see I have a disability, it's quite tough cos people don't believe you. Stressful on our relationship because we were getting frustrated. Maybe if security guard had asked reason for having someone with me.

Kramer: Since I'm in a wheelchair, I felt bad they grabbed me and told be to go up the front. I felt bad and apologising for cutting in and having someone with me.

Paula: I heard a lot about the visible vs invisible disability.

Kim: I found lockdown actually really good. I work so I was able to actually work from home and still keep myself busy. I didn't actually need to go anywhere because my parents do all my shopping, so they were the ones who did it for me.

Tamara: Through this time, I had no pain, my voice was clear, I didn't have the pressure of trying to communicate. Lot less stressful by myself, and with my son and not being in public. Level 1 I'm back to working on my language, going slowly. Supermarkets - horrible very stressful. I broke down every time. I had to know what was happening inside, the reason for the lines. I just needed someone to explain it to me. "Have you been living under a rock". People in public service need training.

Kramer to Tamara: how was your experience as a mum?

Tamara: I live at a bach. I have that mentality of everyday I have to do something. Posting on social media to help the mood. By putting in the public with my son, we just built a waterslide and posting about it. Had to stay in the present because people worried about their jobs. Have to stay on top of my mental health. The lockdown was really easy and really nice because I've had the training to push through.

Kim: I found lockdown good. (more) My parents did my shopping for me.

Kramer: Two weeks into it I found home wasn't a place to relax any more with the work. I needed like Tamara to stay in the moment.

Kim: hi I'm good, I was working

Paula: Was anyone studying in lockdown?

Kramer: Like it was at uni - most of the stuff you can watch online now. I was able to do it through zoom still very interactive for me. Easier than physically going in - lot faster more efficient.

Tamara: I kind of studied as a way to entertain myself and outlet my mind. I did a lot of study on the human connection and how to increase the efficiency of that, we all have that. I created a device you can tap into your self conscious and your heart rate and status and communicate about it. The device can tell you if anything is playing up.

Tamara: I have done all the research needs engineering and coding.

Kramer: Was there anything you liked about the lockdown?

Kramer: What I liked was it gave the earth a chance to heal like after the fires. Seeing the difference it made when we were polluting the earth, and time to myself, got practice cooking and healthy eating. I didn't miss fast food got so used to eating greens and try new things I didn't have the time before.

Josh: Obviously I like the free time I got. Instead of community 45 minutes each way, same time it gave me time for more reps into workout. More time to get a little fitter and enjoy myself a little more.

Kramer: I became best friends with my fridge.

Kathleen: It was the biggest reason for me to stay home. I really like staying home in the warm. I have to try to keep myself and house warm as possible. But my aircon has been broken since beginning of lockdown and they can't come and do inspections so I haven't had a heater so I've had to spend money on jumpers, blankets, so everything put on a halt so other than that staying at home best thing I could do because my arthritis is active. It gave me a chance to recoup. I continually had GP appointments, but we did it on the phone. Now that it is all over, I have my GP appointment at end of week and I get to see her for first time since start of pandemic.

Tamara: I learnt how strong I was through it. Got to lockdown and I was totally prepared for the end of the world. I felt strong, happy I was by myself and now I can carry it forward into the normal days.

Kim: I go out a lot at night with things on and I really enjoyed not having to go anywhere. I also enjoyed not having to wake up as early because I didn't have to travel into work 😊

Paula: There were a couple of things I enjoyed about the lockdown. It was a really busy time and I set myself up in a garage. I kind of felt I guess really privileged in a way to get some things done for our community and get some things sorted. There were a couple of nice family things like getting to see my little boy and two teenage stepchildren and being able to pop in during the day and say hello. My little boy said he enjoyed lockdown because I was home before dinner. Walk around the block, played games, connecting. Those weeks were probably four of the most stressful weeks in the role but also value that time.

Paula: What did you do to stay connected? I loved seeing the videos you were doing, some really neat things the disability community got up and running.

Josh: I can reflect on that too Paula. The increased online presence has made me feel the most connected to this community that I’ve ever been.

You would be the first to see me digitising the way we connect and using technology to amplify our voices. It was a daunting task to create those videos. I had the whole team on my shoulders, also enjoyable to do that and sets a standard for how we communicate. Also connected through gaming with cousins and talking and keeping in contact everyday, most connected we've been in our adult lives. Before that leading own paths. Connecting using technology was great.

Paula: I had to get sharper and making videos at home. I must admit I personally found lots of zoom meetings exhausting.

Kathleen: I kind of cut a lot of people out after my grandma passed because I needed space then gradually let people in. This is the first time I've used zoom. I was calling Facebook messaging and texting. I just called everyone with my minutes on my phone. There are some of my friends who have got into background a bit, I'm going to contact them - are you ok? Video chats on messenger as well - like we are in the same room.

Tamara: My family stayed on zoom, meetings on zoom, Easter hunt - watching finding Easter eggs. We still had a big family holiday - had lunch together by zoom, my sister's graduation. My family stayed really well connected through that - zoom. Connected with friends, catching up, on zoom. I joined up on a lot of autistic Facebook pages, it was really helpful, lots of tips and memes and laugh at my own disability, nice way to connect to myself.

Josh: The most I did was the Thursday Facebook live videos, my connection with rest of disability community was really limited.

Paula: Maybe something for next time.

Kathleen: I have a history of going to America for arthritis conferences, so I have been keeping in contact with them in America. Looks bad, all my girls are getting knee and hip replacements and it's kind of scary. I just communicate with them over there to touch base.

Paula: We are truly in this altogether.

Kramer: One of our I-Lead members was over there in America with basketball. He had to be evacuated back here and then self-quarantine for two weeks.

Kim: A big one for me was my church. I still had church online connecting with each other. Also had online church young adults’ group on zoom. I had a few Skype chats with my friends, and they were really good. We also caught up as a committee and really supported each other and made sure we were still ok.

Paula: I was invited to an interfaith zoom session, because it was so easy via zoom it was something I could on Sunday morning seemed to be really nice connections.

Kramer: what was the first fast food place you went to?

Josh: I was all about where do I get my burge?. Looked at my flatmate he looked at me, we said we're going to Wendy's. No lines, Very calculated, we knew KRC and MCD would be packed. We opted for Wendys. Ha!

Kathleen: Mine was KFC I just wanted some chicken. We ended up cheating and getting it delivered, I didn't want to wait in line see the cars looping around the building.

Kim: Uber Eats - LJ's fish, fried salmon and chips. Hard out craved fish

Kramer: She went healthy!

Paula: From your perspective, young disabled leaders, got I-Lead up and running - what could be done better if in this situation again and two, what do you want to hold on to.

Josh: Start with what was good. The amount of connectivity we had in a time when connecting physically was not allowed it was great. As a community of young disabled leaders - keeping ourselves safe but also emotionally and mentally connected. I thank all of the I-Lead team for that. Things that could be improved - the PPE gear, it was something that was necessary but deemed unnecessary, a little more responsiveness around that - support to those who need it most when they need it not four weeks later.

PPE is personal protective equipment stuff to keep you safe like masks and gloves

Kathleen: A good thing was the masks. I was working at a vets. We were still open in level 1,2,3. I had to quit because it was getting so physical. I had the masks and things but man, do you sweat in those things. I had a mask but found out it only lasts a few minutes but I was using the same masks for days, I used to wear a mask for food shopping but now I don't need to.

I think through this whole thing a lot more promotion for I-Lead and everyone and we should hold onto that and keep our connections as much as we can - I would want to keep all the communication. We have all been scared, we have all had the same worries, waiting in line, nice to see other people going through the same thing. I would definitely hold on to the connections.

Kramer: The whole connectivity great but at the same time now back in Level 1 we should stay connected but not lose the momentum to get out there. Slowly gone back into the dark ages and we aren't physically getting out there like we used to - connectivity is good, but getting out there increasing the presence. Increased support not only benefit, but food and areas - showed before lockdown current need for that to be implemented. Lock down showed areas to focus on and strive for a better community than go back to what it was. We have learnt a lot, next evolution for disability, next step forward.

Paula: We have to be very strong in our advocacy together. Some band aids were put over those gaps and great response was there but we can't band aid over things for the long term. Need to call for change. It's exposed some really big gaps we all knew existed but maybe others didn't.

Tamara: With invisible disabilities the maximum (from Work and Income) you can get is $60, counselling is $100 - they told me you could only go every two weeks. I can't get glasses - sunglasses – I need them to stop my anxiety. Huge issues, zero awareness. Nothing right now. I have to bring it up.

Kramer: Here we have been telling you we have been connected but we have heard from others that we were engaged but others had no access to wifi, school being the only point of contact to get online, lots of disabled young people worried about contributing to their family, worried about the bills. We’ve talked about a lot of positives we experienced but a lot of problems.

Paula: Want to touch on being out and about and presence of disability, I completely agree we have to be seen and heard, challenge how we use online ways to increase visibility. Whatever way possible we do have to "see" disability.

Kramer: One thing it's shown us how hard disabled people are working, employers got to see how hard and efficiently they worked, that's one thing I liked. What we can do in the employment area.

Tamara: I really liked how the earth benefited from this and the environmental factor, felt less stressful, there with your family, seeing all the families going for walks, so many birds around now.

Emotional intelligence, there’s no training for it. Xabilities has come up with a workshop on it, one on one and group ones. Final touches but 100% successful.

Paula: Both you and Kramer made points about the environments, how do we go find a way of being that incorporates all these great things about more calmness, good things for the environment, get things going for the economy so we can prosper but not lose these things?

Kim: I would agree with Josh and Kathleen around the connectivity and its importance. I feel like there was a great opportunity for people to help other people out not only in the community but also some businesses changing their products to create PPE gear and sanitisers. I like how in all most of us were looking out for each other.

Paula: Yeh I agree. I guess we saw desire for everyone to be kind to each other - contrasted with not so nice, people being judgemental, and some of your experiences, I had two occasions lining up in supermarket queues both older people, I thought I'd encourage them to go to the front. People gave me stares or said something - I just thought “stop”.

Paula: What are your thoughts you want to amplify?

Tamara: I think a lot and I'll wake up at 5am and I know how to change the system and write it on the whiteboard. Something that can help with the environmental crisis, mental health, is emotional intelligence. Support for young people learning about this. Younger children going into careers of their passions. All of us here, we are all passionate in our jobs. Put band aids over everything we will never get to that core. This is one of those things that can get to that core.

Kim: How do I follow that? Haha

Kathleen: The one thing I did like, one of the minor things, I had to take my little cousins for a walk. It was pretty awesome that NZ came up with the teddy bears in the windows. That's how I got them up the hill - find the teddy bear! Shows how really diverse and connected we are. It would be awesome if we can get back in touch with our community again after this pandemic.

Kim: I don't have much to add but I feel pretty proud of what we've achieved as a country and how we've all worked together.

Josh: The ingenuity that NZ has and especially the ingenuity of the disability community - how much we can do off our own backs to help people be more connected, if there was anything we could take away it would be that - continue to push forward for I-Lead and awesome stuff we have. Opportunity coming out of level 2, change some systemic stuff and amplify voices - great time to play around with what works and what doesn't.

Paula: Really big thank you to all of you for tonight. I have been asked a lot what have things been like for our communities, conversations like tonight help strengthen the advocacy I can do. The work we all do is hard and sometimes it can feel we have a big responsibility on our shoulders, we are affected ourselves and we live with the nature of our impairment and many others have said it was hard. Keep looking after yourselves and keep reaching out and connecting. I'm a big fan of I-Lead, future of disability rights in NZ you are among the many fabulous young people around NZ. Thank you my lovely co-host Kramer.

Kramer: Thank you Paula - thank you everyone for your amazing comments. One thing that really stuck with me was about the invisible disability and not being treated properly at the shop. Disability 101.

How to work with us and not shove it in a corner. Not losing the momentum, increase online participation at same time as physical. We at I-Lead are advocating for those 16 and 17 to older and moving on to bigger things. Continue to serve our community. Hit us up on our Facebook and YesDisability. We will answer questions on our Thursday video. Thank you, Stephanie and Melody, our NZSL interpreters.

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