

## **Communication Works Transcript**

### **MC Khamani**

Welcome everyone to Communication Works 2024. My name is Khamani, and I'm CENMAC's Student Ambassador, and I'll be your host for today. I'm delighted to be back this year after taking my GCSE last year. It's a great pleasure to see everyone here today. We are going to have a great day celebrating assistive technology in education. Be sure to use, be sure to use the hashtag #CW2024 and #getseen. I'm 17 years old living with dystonia, a physical disability that affects my mobility and causes me to have random tremors. CENMAC has worked for me since I attended primary school, and I've had first-hand experience of the impact a system technology can have going from using big key keyboards and joystick to a surface laptop with some software. I'm now currently studying film and TV at college. I recently completed my end-of-year project, which was made much easier thanks to CENMAC giving me a lighter camera. In the future, I aspire to work in the TV industry, and I'll be around later doing some interviews with exhibitors. I'm also an award-winning young entrepreneur and CEO of KJ's Craft Time that started during the during lockdown, born out of desire to blend creativity, education, and inclusivity.

I wanted KJ's Craft Time to develop my fine motor skills because it's a skill easily lost as children spend more time on electronic devices and I aim to get them to engage more with the real world around them. I've recently expanded our offers to include a range of craft boxes focused on education and a range designed to ignite the imagination and creativity of children.

Drawn in from personal experience, I'm proud to showcase my latest initiative today, a special education needs range, which is launching very soon. As someone with dystonia a physical disability, I understand the first-hand challenges individuals face in pursuing their passions. This range aims to make arts and crafts more accessible by offering aids tailored to meet the diverse needs of every child, including nine different types of specialised scissors for a mix of abilities, as well as ergonomic bosses, grips and non-spill-paint pots. My mum and nan will be manning the stand, so be sure to pass by to find out about it all which is just over there.

I'm now delighted to introduce Kathryn, who is the Head of CEMAC, with her welcome speech.

### **Kathryn Stowell, Head of CENMAC**

Thank you so much, Khamani. It's really fantastic, that you're back with us, and we're really excited to watch your journey as you move into your career, hopefully in television. But we're really, lucky that you're here. So, yeah, thank you.

I just wanted to welcome everyone to Communication Works 2024. Today is about bringing our community together to share and celebrate the talents and abilities and achievements of those using assistive technology and AAC, augmentative and alternative communication. The #getseen, and hopefully you've managed to pick up a badge that you can take away with you, was inspired by Abdi

Omar, who's one of our team members. He highlighted just how important it is to be seen. Many of the children and the young people that we work with often talk about isolation and not seeing role models in their communities and their schools. I think the more that we can share and celebrate the differences in everybody, the more we will mainstream the alternative ways of learning, communicating, and being. We hope that you can take the hashtag #getseen away with you today and find ways to enable the children and young people you work with to share their talents and abilities so that everyone can learn from their unique skills and diversities and strengths.

Our venue today is one big classroom with the opportunity for shared learning between companies, services, visitors, and the many young people coming here today. So, thank you, especially to Charlton Park Academy staff and students who many are taking part in work experience today, but also to the students who are presenting because some of them are doing it for the very first time. We're also livestreaming so that schools can watch the opening keynote.

CENMAC aims to raise the aspirations of everyone working with children and young people using AT and AAC, and to support the equality of access to these technologies. It's therefore important that everyone has access to what assistive technology is available and what's evolving in the field. We're thrilled that we've got so many students, teachers, parents, and professionals attending today. I want to welcome back the companies who have supported our unique event for many years, and a really warm welcome to the new companies and services that that are here today. I hope that the companies also get the opportunity to collaborate and to share so that we can help improve in developments and the implementation of assistive technology. We've also got our international exhibitor's area back and Mary Long, who's the Deputy Team Leader for CENMAC, was lucky enough to be one of the scholar places at the ATIA conference in Orlando this year. So, her seminar, which is the first one of the day in Seminar Room 1, she's going to share some of the highlights and the information about some of the companies that are going to be online in the international area.

Sorry, I'm just going to use my mic. We want to also provide you with lots of media and resources that you can take away with you today to take back to your schools so that you share it in your staff meetings with your colleagues so that you can help raise the #getseen. It's not always possible that we can get people in person. We've just found out over the last few years how beneficial it is having all this technology and online access. We've got a showreel that will be playing with some fantastic films that have been put together by the British Assistive Technology Association. They're free on their website for you to use. We've got Abdi and his AAC Top Tips, and Ellise's Channel 4 film, Welcoming Differences with Cerebral Palsy.

These will all be made available via the website and thank you to Bob Usher from LGfL who's also filming. I know the keynotes were put up from last year and they've been a fantastic resource to share with our community over the last year. So, thanks.

I'm also pleased to say that we've got Pen Mendonca back who's going to be illustrating the event down on the far walls. So do stop by and have a look. I also wanted to thank Bob Sagoo for creating the

Experience Zone down on the far end corner here for young people to try out lots of technology for gaming. Just a quick other few housekeeping. We've also got a raffle. So, thanks for the companies that have given prizes for the raffle. That will be drawn at 1:55 and 2:35. You can sign up to that via the QR codes on the posters. We plan a lunch break over 12:30 to 1:30, and the pies are back from popular demand of last year. Grab yourself something to eat and then make your way back to the stage for one o'clock because we've got a very special performance by Jess Fisher, who uses the Digit controller for making music and will be sharing a brand-new song or piece of music that she's performing.

Fire exits, just follow the signs. There is step-free access to the right through Seminar Room 1 in the kitchen area. I have given you a lot of information, but don't worry, because Khamani is going to be here telling you throughout the day where to go and what's going on, so he will keep you on track.

Finally, I just wanted to add, I work with a really, talented and diverse team at CEMMAC, and today we're celebrating many of the significant achievements of young people here. But we support lots of children all over London and every day, the team talk about the delights of the small-step progress that is made with the individuals we work with, and that's just as important to celebrate so I want to thank them for their continuing ongoing enthusiasm and energy, and along with a fantastic admin and technical team back at the office. Finally, Annabel Dent, who has worked tirelessly to make sure that this event all runs really smoothly. So, thank you very much. And of course, Mark Dale-Emberton, who's the Principal of Charlton Park Academy that CEMAC sits under. He has an ongoing commitment for the innovative work in this field. So, thank you very much. I hope you have a great day. And yes, you can take the hashtag, get seen away with you. So, I will hand back to Khamani.

### **MC Khamani**

Thank you, Kathryn. I've got a mic here. Thank you, Kathryn for your speech. Next, I'd like to introduce our keynote speaker, a young lady called Ellise Hayward. Ellise, will join us virtually today due to a personal situation that has prevented her from making a trip to London. She has completed her GCSEs in 2018, and since then, Ellise has been spreading cerebral palsy awareness by talking about her communication journey through mainstream school. Ellise has been to schools, NHS departments across England, and recently spoke at the Houses of Parliament. Ellise was part of a Channel 4 short film recently and has written a section for a book called SEND Strategies for Primary Years, which is due to be published this month. Over to you, Ellise.

### **Keynote Speaker Ellise Hayward**

Good morning, everyone. Hope you are having a great time at communication works. I'm gutted I can't be there in person. It's such an honour to be the keynote speaker still. I would like to talk about the way that my communication has developed over the years. When I was just three years old, I had a speech and language therapist. She assessed me, and then I was given a communication book. This was a personalised book of photos and symbols. It had lots of pages with a menu and the vocabulary categorized so that it was easier to access. My support would look at where my eyes were looking at all if

the page was big enough that I was able to use my fist to touch the picture. When I started school, staff had to be trained in how to use my book with me. It was also at this point that I started to use switches like Clicker to support my access to writing. Using switches was an extremely time consuming and slow process. My mind worked so much faster than I was able to record. I remember the frustration, but I kept my cool and managed to show everyone what I was capable of.

I was then able to move on to using a joystick to access the computer. This makes things a little quicker, although my accuracy was not great, and mistakes were made.

So, what I gained in speed in one way, I lost in another through having to make collections. For my communication at this point, I was loaned a communication device called a Mobi. It had been personalised and programmed just for me. Both my communication book and Mobi had to be updated regularly with new vocabulary so that I could access my lessons and, also so that I could socialise with my friends. I could only write what was programmed in.

When I was finally given the opportunity to try eye gaze, with a laptop at the age of 11, initially, it was tricky to make sure that I only clicked on things that I wanted to click on. But I discovered I was a quick learner, and I soon mastered this. By this time, I was able to read and write at a similar level to the rest of the students in my mainstream class. I used an on-screen keyboard using my eyes to type, I managed to complete work which was set by the teacher, and often I would produce more work than some of the students who were writing.

My problem was I didn't like the voice. It was very computerised, and I felt embarrassed using it. I felt different. Therefore, my support assistant would stand to the side or behind me so that they could read what I was saying. This went on for most of my time in secondary. Until I met Lynn, she suggested that I should be assessed at Crystal Communication a service for a new communication aid. She also looked at different voices. This eye gaze was so much faster, and I chose The Queen's voice. Together, we found the Queen's voice, which I liked very much. It was when I began to use Queen Elizabeth II's voice that I decided to allow my computer to talk for me instead of relying on someone else to read everything that I typed. For the first time in my life, I felt comfortable and proud to be able to talk. Following the referral and assessment for a communication aid, I was allocated with this device I am using today. I always look on the positive side and try my best in everything. I'm a strong-minded person and set my goals for me to achieve.

My disability isn't a barrier. I'll always find a way. I'm forever pushing myself to be the best version of myself, even though I am slower, and things take me a lot longer. I'll get there eventually. We all have challenging times and struggles in our lives, but we must keep on going to succeed. Working hard and achieving is one of the best feelings in the world. It's okay to take a step back to recharge, but we should always get right back up and try again. There's always a light at the end of the tunnel, and there's always someone to speak to. You are not alone. I hope you have enjoyed my story today. What I'm trying to say is I have never, never known what it's like to talk, run, walk, or feed myself without struggling or being in pain. I'm never sad because I'm here and alive and life is worth living. It's beautiful. I hope you understand

what I have been through and how I have overcome my challenges. I will get more independent. Nothing will stop me ever. I am me. I am loved very much. I'm just a young lady who may need a little help.

Thank you very much for taking your time to listen to me today.

### **Kathryn Stowell**

Thank you so much, Eilise, just I'm going to stand here so she can see me. When I spoke with Eilise last week, because sadly, she couldn't be here in person today, I said to her, "Can I share some of your amazing achievements?" She truly is unstoppable. She has something like 14,000 followers on Twitter. She's spoken at the Houses of Parliament, and she's been part of the Channel 4 film, Welcoming Differences with Cerebral Palsy. I'd like to actually share, that with you now because I think you get a real sense of her personality. You're also a correspondent with the Jil Dando. A very, very impressive person. So, we're just going to play your video for everyone.

### **Welcoming Cerebral Palsy - Channel 4 Film**

#### **Joe**

I'll dance towards the girl and I'll literally just drop to the floor, and then automatically what they do, is that they'll say "You okay? You okay?".

#### **Abbie**

Save me!

#### **Joe**

And it's just a perfect icebreaker to speak to them.

#### **Ellise**

That's one way to get a girl.

#### **Joe**

It works nine times out of 10. It's not good for kids, and it's not clever.

#### **Abbie**

The type of cerebral palsy that I have is hemiplegia. So, it affects the whole left side of my body, from my eyesight, down to the size of my foot, and everything else in between.

#### **Joe**

The type of cerebral palsy I have is called spastic diplegia. It affects my mobility, my coordination.

#### **Ellise**

And sometimes speech and vision. Everyone with cerebral palsy is completely different.

**Abbie**

Cerebral palsy, generally, isn't non-visible, but for me it is. And I think I've always struggled with not where I fit, but how to manage it and how to unpack people's interpretation of what they think cerebral palsy is.

**Ellise**

I'm nonverbal. At school, I was made aware of the power that I could have if I used my voice output. My specialist adviser downloaded a voice that sounded like the Queen for me to trial. I love the idea of being Queen Ellise.

**Joe**

One of the most frustrating but common misconceptions about cerebral palsy that my IQ is affected. This is not the case for me. I pride myself on being really, quite academic.

**Abbie**

Yeah, I think people communicate with me very differently once they hear the word cerebral palsy come out of my mouth.

**Ellise**

In the past, I have been treated like a baby, and I have been totally misjudged and patronised.

**Joe**

The other part would be staring. It's very common, and it's extremely difficult for me to distinguish between if people are looking at me in admiration or they are looking at me in a judgemental way.

**Abbie**

And it's really hard, right? Because most of the time people aren't trying to be nasty.

**Joe**

It's about not assuming that everybody with a disability struggles with learning.

**Ellise**

Just because I'm non-verbal or someone's speech is slurred doesn't mean we don't understand you, speak to us as you would anyone else.

**Joe**

People assume because I'm disabled, I'm going to be easily offended, which isn't true. I try and find the funnier side about my disability, and I find it easier to deal with.

**Ellise**

My sister once said, I'm so lucky to have you as my sister. I felt proud, and with the next breath, she said "We get to skip all the queues".

**Abbie**

Travelling can be really stressful, like trying to get to a handrail and not being able to, that's really scary because my balance is rubbish. I could just fall over. And my friend turned around to me and she was like, If you just beep really loudly, like you're a truck reversing, people will move out the way.

So, I don't know. I don't mean that person is like. Follow the rules and follow the signs, but follow the rules and follow the signs. Because like if you're going up and down the way you should be, it's immediately easier for somebody to access the handrail because the handrail is not decoration. It's support.

**Joe**

Not all disabilities are obvious.

**Ellise**

I sat in a car with no movements. I look no different. You can't judge a book by its cover.

**Joe**

This man came walking over to me. You're not disabled. You don't look disabled. You shouldn't be parking there. And I got out of the car, and it was a very awkward situation.

**Ellise**

Isn't it hot under these lights? Doesn't the Queen have someone to fan her?

**Joe**

When I'm moving around, my expenditure of energy is a lot higher. If I walked a mile, it would be the equivalent to somebody else walking three miles.

**Abbie**

When it comes to people using mobility aids, like wheelchairs, crutches, frames, anything, is there to help in whatever state of fatigue, pain, or support you need, it doesn't necessarily mean that you have to use it all day long, every day, and that it's like attached to you.

**Ellise**

Please be respectful of everyone in a wheelchair as there are many reasons why people are in them.

**Joe**

People try and kind of put their arm under my arm and try and help me across the road. I work so hard for that independence that I want to have that independence for as long as I can. I'd rather people come and speak to me. It might not be the same for everyone.

**Abbie**

With a disabled person and somebody with additional needs, let them tell you what they need.

**Joe**

The more people that are aware, the less frustrations, people like me with different disabilities will experience.

**Abbie**

And it's just giving the person, the voice, and the platform to say what they need, which is where you can do the most learning. There are things that I need help with, sure, but I know what they are. One really positive example is a job I did earlier this year. I immediately felt so welcomed because prior to going in, I talked through my access requirements with the Access Coordinator. They could have just had that piece of paper and stopped there and gone, we've got it written down what she needs. But they actually discussed this document with me and gave me the chance to explain that my condition does fluctuate from day to day. I didn't feel othered. I didn't feel that I was asking for too much. And it's because they listened to me, and they gave me a chance to speak rather than assuming. And that's such a big thing.

**Ellise**

We hope you've picked up a thing or two that's helpful. And if you haven't, just blame it all on Joe.

**Video ends**

**LGfL presentation on Universal Design for Learning presented by Daniel Davies**

This video has closed captions.

**Jess Fisher – Musician****Jess**

Are you ready for some music?

Audience: Yes!

**Jess**

So, what you're about to see are my original pieces. The first one is called Trees and I wrote it during Lockdown because my college was surrounded by beautiful trees and I was channelling my emotion and how I felt through lockdown. So this is the first song. Now I have a question for you all. Are you good at cheering?

**Audience**

Woo Hoo

**Jess**



You can all do better than that!

**Audience**

Woo Hoo

Jess

So, the only reason why I was able to make my music is because I use this. This is my Composer and it's created by Digit Music and I created this whole piece of music by using the Composer. So, give a round of applause!

**Audience**

Clapping and cheering

**Jess**

So the first song is called "**Trees**" and I hope you will enjoy.

**Music plays**

**Audience**

Clapping and cheering

**Jess**

This song was only released a few weeks ago. And you guys are the first to hear it live!

**Audience**

Cheering

**Jess**

So, no pressure on me. Can you all talk amongst yourselves for 2 minutes while I do a bit of fancy work. Thank you!

**Music plays**

**Audience**

**Clapping and cheering**

**Jess**

If you want to find out more about my music head on over to the Digit Music stand.