Exploring the role of technology in the lives of young people living with visual impairment

Number 5 – June 2022

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Welcome

Welcome to our fifth biennial Mary Kitzinger Trust newsletter.

The aim of the Trust is to share research, experience and insights and help stimulate the interchange between research and practice relevant to children with visual impairment.

In this newsletter we hear from researchers, practitioners, and those with lived experience of vision impairment about research, practice and developments in technology. They have contributed inspiring pieces on how we can make technology inclusive and the particular benefit of technology for young people with vision impairment. There's also signposting to resources and relevant research papers. Enjoy!

Thank you to you all for supporting the Mary Kitzinger Trust over the years and we hope to see many of you at our next event in Autumn 2022 (see below), we will be circulating details shortly.

Alex, Rebecca and Elena

Mary Kitzinger Trust, Organising Team

www.marykitzingertrust.org

Future dates for your diary:

- **Saturday 8th October 2022 – Face-to-face workshop**
  UCL Institute of Child Health, London
  "Promoting successful futures for young people with visual impairment"

- **Saturday 6th May 2023**
  Details to be confirmed.

‘Removing barriers to employment for people with visual impairment, accessible technology and listening to students’

Interview with Melissa Fanshawe, Senior Lecturer in Mathematics Curriculum and Pedagogy

Hi Melissa. Please tell us a little bit about yourself and your background.

Hello. I am a Senior Lecturer in Education at the University of Southern Queensland. I began working as a Classroom Teacher in 1999 in a Central Queensland school. After a few years, I met a student who was completely blind. The next year I was offered a role in the Early Development programme, which was early intervention before school. I then went on to work as a District Advisory Teacher for adaptive technology. I worked in advisory roles before going into a small school as Principle. In 2007, our third child was born with Peter’s Anomaly, with no light perception. He had a corneal graft at 9 days of age. In 2011, I went back to work part-time as a Deputy Principle in a school in Brisbane with a number of students with blindness and low vision. In 2015, I completed a Masters in Special Education (vision impairment) and now have entered into Academics at the University of Southern Queensland.

How did you become interested in research on visual impairment?

My experience started professionally and ended up somewhat lived experience! Most people come into the field because they know someone with blindness or low vision. For me, I worked in the field and then had a child who is legally blind. Through numerous sports and social groups my son was involved in, I saw a disparity in experiences for students. I wanted to be able to find what it is that made a difference, so each person had the same opportunities.

You have recently completed a PhD in visual impairment. Can you tell us about your PhD work?

Of course. It’s under examination at the moment, so fingers crossed! I wanted to know why despite improvement in technology and understanding of disability, there is still such low employment rates for people who are blind and have low vision. I looked at barriers and enablers for participation in learning and skills for future employability, specifically for students with blindness and low vision in mainstream secondary schools. It was really interesting as I used a Bioecological systems model to interview students, their parents, teachers, advisory teachers, policy makers, employers and people with lived experience. I really gained a lot from speaking to so many stakeholders. I found that when students had continual and sustained access to disability specific skills they were more likely to be able to participate in learning. I am hopeful that students who have been taught the skills to be independent in accessing their work, will be confident and prepared for the workforce.

When did you get interested in access technology for the visually impaired and what brought about this interest?

It must have been 2003 when I worked as an Advisor for Access Technology and a lot has changed since then! I used to braille a lot of things with a Perkins’ Brailler and if I made a mistake, I had to redo it! In this job I had the time to listen to what made access best for students. I think listening to the voice of the student is so powerful. Since then, I have really seen that with access to the right tools, knowledge of how to use them independently and a supportive system, students have agency in their learning. This has had a powerful influence on me.

Interview with Melissa Fanshawe continued…

You have also been involved with Vision Australia, the leading national provider of blindness and low vision services in Australia. Can you tell us a little bit more about the work you have done with the organisation?

Yes, I have been working with VA on a research and design project to create nationally recognised certificates for disability specific skills. These certificates have been written and reviewed by over 25 experts in the field and the scope and sequence mapped out by nearly 100 stakeholders. The result of these certificates is a series of competencies and performance indicators to progress students through the disability specific skills required to be independent in education and employment. They include things such as setting up your workspace, access technology, working in teams and personal sustainability in the workforce. The certificates in Access Technology have all been approved and are sitting on the national training register, ready to be delivered in 2022.

What are some lines of research that you have identified in your work that you think warrant more attention by academics, clinicians and practitioners both in Australia and internationally?

So much! My research looked at students in secondary schools, but early intervention is so important too. I think there is a lot of research to show that disability specific skills are important for students to 'learn to access' (McLinden et al., 2017). Currently we have many advisory teachers who implement this, based on their past experience, training and some great resources that are available. However, with variations in class teachers' qualifications and experience, I think we need to support them, by creating developmental sequences and guidance on how students can be supported. I'd love to see educators aware of the importance of working together with advisory teachers and parents to support students. I'm also really interested in the work of some Australian clinical researchers such Sue Silveira and Lynne Loh, who have been looking at functional vision.

What work are you currently involved in and what does your research hold in the future?

I will continue to be involved in the rollout of the Vision Australia certificates, as I am so excited that VA want to ensure equitable and free education for students with blindness and low vision across Australia. I also have volunteer roles in Vision Australia as an education ambassador for Braille Lego, the South Pacific Educators of Vision Impairment (SPEVI) and the Australian Braille Authority.

In 2022, I really hope to have my PhD conferred! My grandpa is 96 in February and he has a PhD, he will be really excited to see me graduate, fingers crossed! I continue to work with my research partner, Dr Melissa Cain from Australian Catholic University on many projects around students, parents, and teachers and a SPEVI project focusing on online learning for students with blindness and low vision across the South Pacific. We also have international partnerships looking at physical activity with Esteemed Professor Lauren Lieberman and Dr Ellen Armstrong, and mentorship for young people with blindness and low vision, with our Canadian friend, Dr Mahadeo Sukhai. I am also very excited about the work going on in VIEW (UK). Oh, of course I also have my day job which is teaching at the University of Southern Queensland. I teach my students how to be inclusive in mathematics. I love that too!

Thanks Melissa!

Read Melissa's recent publications on improving the online learning experience for students with visual impairment:

Cain, M., & Fanshawe, M. (2020). "Talk to Me!": Empowering students with a vision impairment through audio E-Assessment feedback. In technology-enhanced formative assessment practices in higher education (pp. 1-19). IGI Global.

Cain, M., & Fanshawe, M. (2021). Expectations for success: Auditing opportunities for students with print disabilities to fully engage in online learning environments in higher education. Australasian Journal of Educational Technology, 37(3), 137-151.

Tualaulelei, E., Burke, K., Fanshawe, M., & Cameron, C. (2021). Mapping pedagogical touchpoints: Exploring online student engagement and course design. Active Learning in Higher Education, 1469787421990847.

‘Online teaching, assistive technology, advances in technology and social media’

Questions and answers with Holly Tuke, Disability Blogger, Freelance Writer and Social Media Officer

Hello Holly! Start by telling us a bit about yourself.

Hello! My name is Holly Tuke and before I worked within the charity sector, I worked as an Assistive Technology Advisor within higher education – a role I did for nearly 4 years.

I’m passionate about accessibility and assistive technology.

I am registered blind due to a condition called Retinopathy of Prematurity, as I was born at 24 weeks.

When I'm not working, I can usually be found tapping away at my keyboard writing articles for publications and creating content for my own blog. Oh, and I also do love a bit of radio presenting as well!

In my free time, you can usually find me at a concert (I probably go to way too many), making memories with my friends and family, spending too much time on the internet or reading a good book.

Talk us through a typical day of an Assistive Technologist.

When working as an Assistive Technology Advisor, my days were always varied. I’d start the day off doing the usual admin tasks – checking my calendar and responding to emails. I’d then have appointments with students throughout the day. These would range from an initial session to order any software and equipment they were receiving through DSA (Disabled Students Allowance), setting up the software and equipment they’d received or demonstrating how to use the software. The sessions would be tailored to each individual student, some would prefer shorter sessions focusing on one or two specific areas, whilst others would prefer a longer session covering a range of topics.

After the session, I’d return to the office to do the required admin and any follow-up enquiries to suppliers or other teams within the University where necessary.

When I didn’t have appointments, I’d attend meetings with colleagues, do any promotion of our service throughout the University, such as offering quick drop-in sessions and social media promotion, and I would also be there to support staff with any of their own assistive technology enquiries.

It was important for me to keep up to date with the latest advancements and updates within the world of assistive tech, so I’d attend training sessions and webinars when appropriate.

How has online/remote teaching during the COVID-19 pandemic affected the students with VI that you have worked with during this time, and any recommendations for making remote teaching more accessible?

When the shift to online/remote teaching was introduced, it was all about figuring out the accessibility of the platforms that were being used to carry out online lectures and seminars. Like many of us, the majority of students weren’t familiar with platforms such as Microsoft Teams and Zoom. It was all about supporting them to use it independently, and often showing them the shortcuts that would be useful. Being able to navigate such platforms confidently is key.

Interview with Holly Tuke continued…

We'd also have to look at possible adjustments for some students such as the best way of taking notes and viewing lecture slides whilst tuning into the lecture. These adjustments could involve using more than one screen, or using a couple of devices to carry out various tasks. It's vital to listen to the student.

In regard to adjustments, one of the most important things you can do is to make sure that your content is accessible. This goes for both online and in-person teaching. However, remember that screen readers don't read out what's on the screen when you are sharing your screen, so make sure they have this content in advance in their preferred format.

For platforms that have the chat box function, limit the use of this to when it's really necessary. It can be tricky to listen to both someone speaking and a screen reader at the same time, not forgetting keeping up with the chat!

At our recent Mary Kitzinger Trust workshop, we heard from Ida Sodhal Utne about how the increased popularity among adolescents of photo and picture-based social media platforms can be exclusionary for young people with visual impairment. In a recent blog, you highlight the positives of social media for connecting the vision impairment community and in educating others. Do you have any thoughts about how we overcome some of the barriers for adolescents with visual impairment in accessing the same social media as their peers?

Firstly, everyone should have access to social media platforms should they wish.

I think we all have a role to play in ensuring that blind and vision impaired young people have access to the same content as their sighted peers, whether that is written, photo or video content. Making content accessible is pretty much the difference between a blind or vision impaired person being able to access it or not.

Take a picture on Instagram for example. By adding Alt Text (an image description) you are making that photo accessible to your blind or vision impaired followers. It literally takes less than two minutes to write Alt Text, but it makes the world of difference.

Take the time to educate yourself on how you can make your content accessible. Remember that small changes go a long way!

As someone who works within social media and also is a consumer, accessible content makes me feel included.

I also think we should encourage young people to fill their feeds with the content they are interested in, rather than the content they feel pressured to consume.

Ultimately, accessibility should be at the heart of everything we do. And that goes for app developers as well. Everyone should be able to access social media platforms regardless of what accessibility features or assistive technology they use.

What recent technology advances have made a big difference to the lives of young people with vision impairment in the last couple of years?

Apps such as Seeing AI are broadening the landscape for blind and vision impaired people. Having a number of features built into one app is amazing and can help to make everyday tasks much easier and less time consuming.

Similarly, the introduction of NaviLens is transforming tasks such as reading information on packaging. We are now gaining access to information that was previously inaccessible, something we need more of.

I love it when mainstream products are accessible straight out of the box. Smart speakers such as Amazon Alexa are fully accessible, and have a range of uses for enhancing our daily lives.

Interview with Holly Tuke continued…

As we all know, specialist software and equipment can be expensive. Braille displays and notetakers can come with a hefty price tag, meaning that many blind and vision impaired people do not have access to these products. The Orbit Reader is a great device, at a more affordable price. I hope that this is only the beginning of such products.

This list wouldn't be complete without the mention of the advances in accessibility for phones and tablets. Apple and Android devices host a range of accessibility features, and act as a gateway – from education, to work, and our personal lives.

What technology accessibility developments would you like to see happen in the next 1-2 years?

I'd like to see accessibility at the core of society. From the online world, to when out and about in cafes, shops and restaurants.

I'd like to see more mainstream brands and companies embrace accessibility and most importantly, think of their disabled customers. I hope for more products to be affordable, giving everyone the opportunity to use them should they wish.

What are your top 5 digital resources that you would recommend to young people with visual impairment?

1. **Blogs and content creators:** Surround yourself with people that you can relate to in one way or another. Find people in your community. Facebook groups are also great for asking questions.
2. **The Big Hack by Scope:** The Big Hack by Scope | Resource Hub - The Big Hack
3. **AppleVis:** the leading resource for all things apple products for the blind and vision impairment community AppleVis
4. **Microsoft accessibility guides and resources:** Accessibility Guides & Resources | Microsoft Accessibility
5. **Blind Guy Talks Tech Podcast:** Blind Guy Talks Tech

'MyEyes, a child-appropriate app for self-reporting of vision-related quality of life and functional vision'

Alexandra Robertson, Ameenat Lola Solebo, Minu Choi, Simon Kanani, James Malkin, Daiana Bassi, Sue Connor, Yun Fu, Dean Mohamedally, Gemma Molyneux, Graham Roberts, Neil Sebire, Jugnoo Rahi, UCL Department of Computer Sciences, GOSH DRIVE, UCL Great Ormond Street Institute for Child Health.

Funding from Fight for Sight UK, Guide Dogs and Great Ormond Street Hospital Children's Charity

The VQoL_CYP and FVQ_CYP are validated patient-reported outcome measures (PROMs) which capture vision-related quality of life (VQoL) and functional vision (FV) and are designed for use by children and young people living with VI, to capture children's own perspectives of the impact of visual impairment (Tadić, Robertson, Cortina-Borja & Rahi, 2020; Robertson, Tadić, Cortina-Borja & Rahi, 2020). They are currently used as paper-based questionnaires in research and routine clinical practice. However, clinicians and families would benefit from digitalising the process, allowing patients to complete questionnaires electronically with data automatically collected into a database for analysis.

MyEyes, a child-appropriate app for self-reporting of vision-related quality of life and functional vision continued…

In collaboration with UCL Computer Science, through the Industry Exchange Network, researchers at Great Ormond Street Hospital and the UCL Great Ormond Street Institute of Child Health developed a proof-of-concept app which was created to deploy both the VQoL_CYP and FVQ_CYP digitally (collectively known as "MyEyes"), complete with a database for analysis. The web application was developed using Django with a PostgresSQL database. The mobile app was developed using Ionic.

Digitalisation of MyEyes was successful, resulting in a mobile app which can be downloaded to patients' phones or tablets. There are several features of the app which target the unique, complex functional difficulties children and young people might experience when using electronic formats. For example, text can be enlarged on the app, and read aloud to the user. We made sure the app can provide audio and sensory feedback, to clarify which response option the user has chosen, and at what stage of completion they are.

The presentation of response options was designed by researchers with expertise in psychometric measurement, to minimise any bias that might be introduced by participants having to scroll to find their desired response option.

This project demonstrates that PROMs can be digitalised, making data collection a more efficient process. The MyEyes app has many advantages, including the potential to improve children and young people's *experience* of completing PROMs. We can now give children and young people the *option* of completing PROMs at home, for example, ahead of their clinical appointments, and potentially minimise any input from parents, ensuring we capture true self-report.

The MyEyes app also affords patients the means by which to complete PROMs (and submit their PROM data) at pre-specified time-points, allowing clinicians to observe, and interpret PROM data in advance of clinical appointments, and over time.

If we can provide clinicians more information about their patients' eye conditions, and how they change over time, using an electronic app, such as MyEyes has the potential to benefit clinical decision making, ensuring patients receive the best treatment at the best time for them.

Note: MyEyes is a proof-of-concept app which is not currently available for use. For any questions/details of future development, please contact Professor Jugnoo Rahi (j.rahi@ucl.ac.uk).

‘Apps, animations, and erupting volcanos!’

Interview with Elodie (11-year-old living with visual impairment) and her mum Michelle.

Hi Elodie! We have heard that you’re creating some games. Can you tell us a bit more about the games?

You’re right, I am trying to make games. I made this ‘Pop it’ one on my iPad (poppet game). Basically you go into it and you can choose the shape or colour of your ‘Pop it’.

Brilliant! And how did you learn to create this kind of thing?

I found an app and thought I’d try it out. It’s like programming but you don’t actually have to type in the code, there’s connective blocks and you put them together to make what you want.

Mum: You are also very good at making animations too!

What are your animations like?

There’s one I call “a day at the beach”. It’s basically a picture of the sea and there’s a big wave that crashes on the sand over and over again.

And do you use your iPad to create these?

Yes, it’s just frame by frame so you draw one thing, then you press the pause button. And then the shadow of that previous one you drew will show up. Then you draw the next movement in your frame, and so on, until you have an animation.

Mum: You did a volcano too, that was good. It was an erupting volcano. **Animations are actually really fun and you can make things that look really good really quickly.**

And when you are using your iPad, does the iPad speak to you?

Yes, I’ve got voiceover. I use gestures such as swiping left or right to move things, or double tap to activate what I want. **It’s really easy to learn.**

Mum: We got you your first iPad when you were two. The first things you used to watch were nursery rhymes! We put those on YouTube. You listened to them and after a while you realised that if you touched it, it could move and stop playing, or you could play it again. **You slowly figured it out!**

And how old were you when you did your first animation or game?

I was 9 years old. I was just self-taught.

Mum: And you played some of the games that made noises. Those were good. We used **BallyLand apps** which are designed for blind children. They take you through all of the gestures. You learned them through use of the **Ballycopter** game**.**

Ballycopter, Tinkerball and Squeaky.

Mum: There was one game where we went to the park and explored all the noises, the pond and the sandpit, the kids playing.

Yeah, that was really fun!

Mum: You double tap and can hear the noises. So if you are in the sandpit, you can tap it and you hear the children playing. So, it was really to teach you how to move your fingers on the screen.

And there are also different levels, so you don’t get bored of it. And you don’t even realise that you are learning. **My iPad has got voiceover recognition but some apps don’t work very well with it.**

Mum: Some apps are very good, and some not good at all. Elodie figured out you can ask, and if something was not accessible with voiceover, she could use the artificial recognition to make it work.

Basically, if you have an app that does not work very well with voiceover, you use the router to find the screen recognition to turn it on and basically it figures out what all the buttons might be and you can play the app. And if that did not work, I could always email the developers [smiles to herself].

Have you made any videos or movies?

I made a couple of iMovies of things and there is an App called **GarageBand** that I used to make theme tunes for my movies.

Mum: I remember when she started trying to do all this stuff, **I thought "it's not going to be accessible".** But Elodie has a huge amount of self-determination. We set it up so that she could fingerprint any apps that were free to download. There were hundreds! Every night we would look through it until we found the ones that worked. Since then, she uses technology nearly in everything. **To read things, scan things, it's part of her life.** She can do online shopping. She can do my supermarket shopping quicker than I can!

Lots of kids seem to be very receptive, they sit until something comes to them. I think things could be a lot better for kids, they need to get the right technology at the right time. You know the charity Guide Dogs have given kids an iPad or a phone as part of their project at the end of lockdown, you could apply through VICTA (*scheme not running anymore*). I think a lot of parents don't know how their kids can use an iPad. For example, **if the kid doesn't know how to use it, they might just give up?**

Elodie has an amazing ability to organise herself in space and her memory. She is very good at Rubik's cubes. I think these things have made her really good at using the iPad. People do not realise that when we use technology, **it's life skills we're learning, not a game.**

Have you shown the things you've made to your friends in school?

I have sent a few things to my friend. It is my friend that suggested the animation App to me.

Mum: **I think if you learn technology young, it becomes part of your life, part of your play.** You are just on this trajectory. It can help you in secondary school. It can help you in life, even University.

Have you identified any gaps in technology?

Mum: Absolutely. Even in the last 2-3 years there has been a huge, massive shift to digital learning for all children. However, there was a big gap when Elodie went off to school. I suppose parents may not have had equipment at home, so there were access issues. There are also funding issues, everything needs to be updated every 3 years, and not every parent has access to an iPad or technology, so lots of kids miss out. There is no framework for development of technology for children. There should really be a National programme from preschool age to be given an iPad. It's about cause and effect. Every kid can touch something and make something happen.

One of the charities here want to create an 'App Group,' a group for teenagers. Something that is shared so that kids can meet up on and share technology, so that body of knowledge grows. You know kids can learn from other kids.

Yeah.

Elodie, are there any Apps or games you would recommend to other kids to use?

Swordy Quest. It's like a mythical adventure. You get gems and stuff. It's really accessible.

Mum: **Ballyand for younger children,** 3-4 year olds. I think Elodie's journey is really important and I think other kids would like to hear about it. If I was a parent I might think Apps are so overwhelming. Where is the starting point? What is going to be a hit for the kids?

Yes, I completely agree. This has all been really interesting. Do you have any final comments?

Mum: I remember when Elodie was in Year 1 at school. They brought in a trolley with laptops when they were doing computer and they gave Elodie some Playdoh. **I thought "she is the one kid in here that this computing should be the most important thing for her!".** If they are going to navigate the world using navigation software, they need to be savvy with this, and use it to their advantage!

I think the thing that helps you navigate topographical skills from an early age is early orientation and mobility. Going about on your own, not being led, using your cane. **Just because you are blind, it doesn't mean you brain doesn't learn!**

Mum: I would love to see more kids using technology and Apps and speaking to each other. We know that Elodie's self-esteem has flourished because she has been given the opportunity to do things for herself.

But I guess for Elodie, **technology is her eyes.** That is her everything. She conducts her life through that. She does everything on it.

The special curriculum for VI needs to do more on technology. There needs to be more of a scaffold there. For example, what technology is best for what age? How do we do that? There needs to be a proper learning programme in that, perhaps one resembling the one for sighted children. The kids need to learn to use technology to access the curriculum, and for someone to understand what kinds of skills are appropriate for the developmental age. We cannot put kids in front of the computer and expect them to be able to work it. **I suppose it's reach for the stars?!**

You're completely right. Children need to have the foundations and build the skills to help them do that.

Thank you both Elodie and Michelle for taking the time to talk to us.

Watch Elodie's BBC video here:
https://www.youtube.com/watch?v=pf7WHdUptls

"I'm blind but technology helps me animate"

We thought you might like to know about…

our new book!

Collaborations in the field of childhood vision impairment and networking via the Mary Kitzinger Trust have contributed to the publication of "Children with Vision Impairment: Assessment, Development, and Management" (Edited by Naomi Dale, Alison Salt, Jenefer Sargent, and Rebecca Greenaway). Published by MacKeith Press in December 2021.

This book includes chapters from multidisciplinary experts in the field covering approaches for improving function, learning, and activity. Two of the chapters have particular relevance to the theme of 'Technology':

- Technological aids for spatial perception and mobility
  by Monica Gori and Giulia Cappagli
- Low vision aids and assistive technologies for reading, learning and education
  by Michael Crossland, Annegret Dahlmann-Noor, and Ngozi Oluonye

Find out more about the book:

https://www.mackeith.co.uk/blog/book/children-with-vision-impairment-assessment-development-and-management/