Marie Johnson
CEO
Centre for Digital Business

I would like to begin my talk today by acknowledging the traditional custodians of the land where I am giving this presentation in Canberra - the Ngunnawal people.

And I would like to acknowledge the traditional custodians of the lands where many are gathered listening to this presentation.

In the *2020 International Year of the Nurse and the Midwife*, I would like to especially acknowledge all nurses as humanitarians.

I would like to sincerely thank Mr David Moody and the NDS for the incredible privilege of giving the 2020 Kenneth Jenkins Oration.

Introduction

Distinguished guests, and all people listening to and reading this Oration in other places and at other times.

A few days ago on 3rd December, we celebrated the International Day of People with Disability and in this Oration I will be exploring the UN Convention on the Rights of Persons with Disabilities as a driver of innovation.

In preparing for this Oration, I read many of the previous Orations and of the remarkable people who gave them.

In the 1996 Kenneth Jenkins Oration, Sir Ronald Wilson, President of the Human Rights and Equal Opportunity Commission reflected on the magnificent breadth of vision of Kenneth Jenkins and the challenge he put to the world, for people to engage in sustained practical action.

Sir Ronald presented a choice for Australia:

"*Are we an inclusive society that values the participation of all its members?* "

I am not only incredibly humbled by their legacy, and thankful – but emboldened to make my own contribution to that legacy.

Our choice today is this:

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To accept and include people with disability as the drivers and designers of radically inclusive innovation.

Radically inclusive innovation that moves beyond the theoretical concepts of “choice and control”.

That excites society to accept, welcome and acknowledge people with disability as the creators, designers and drivers of innovation that benefit *all* society.

Radically inclusive innovation that creates new servicing paradigms and ecosystems, freeing people with disability from the control of indefinite survey, study and examination by others.

Radically inclusive innovation that challenges and upends design bigotry, moving beyond people with disability being seen as mere recipients of the limited choice of someone else’s good ideas.

My perspective is shaped by three intersecting domains in my life.

I was the Head of the NDIS Technology Authority responsible for the technology business case, co-design, participant experience, innovation, emarket concepts and Nadia.

I am a global technologist, entrepreneur and humanitarian. I am deeply connected to and active in driving cutting edge innovations in artificial intelligence, cyber, the tech and health-tech industries.

And above all, I have the lived experience of disability in my family.

My husband suffers a chronic genetic heart condition, with multiple heart surgeries. He has significant neurological and movement disorders and is losing the use of his hands.

My beautiful daughter has a complex combination of psychosocial disability and physical disability, and has suffered some horrific experiences.

And two of my grandsons have cognitive and communication disability.

When I am told by people in power “that we don’t have time for this future stuff...”, that ignorant and bigoted attitude sentences us and many people, to unnecessary hardship and unrealised potential.

Over 20 years, the lived experience has caused me to fight the status quo, institutions and those attitudes.

So the quote from Steve Jobs in the 2019 NDS State of the Disability Sector Report, resonated deeply:

“*You have to be burning with an idea, or a problem, or a wrong that you want to right. If you’re not passionate enough from the start, you’ll never stick it out.”*

These three intersecting domains of my life are threads throughout this Oration.

I will frame this discussion using one of the most remarkable episodes of human endeavour in the realm of extreme conditions – the NASA space programs – as perhaps an unlikely comparator of vision, risk, design and innovation.

I have studied NASA formally and have visited the Kennedy Space Center twice, including on-site to witness the launch of the final Space Shuttle Atlantis. An event that is breathtakingly magnificent.

What can the extreme conditions of space and disability teach us?

Where assumptions are upended; innovation is catalysed at the edge; belief systems and doctrine challenged.

How do you design something that has never been designed before?

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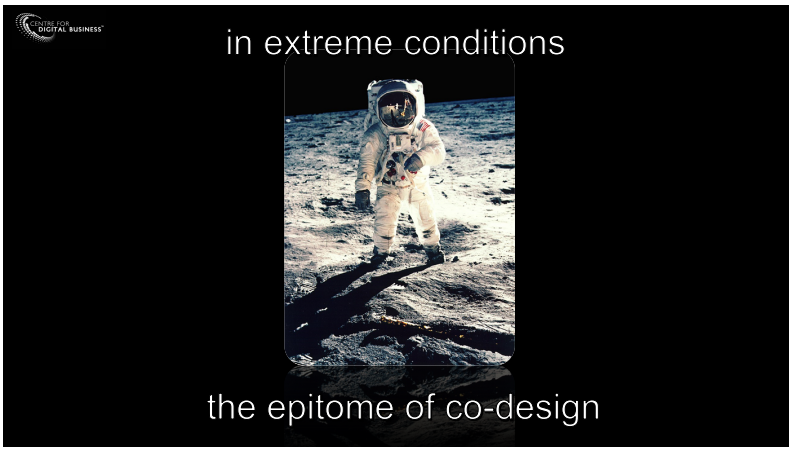
In Extreme Conditions ~ Co-Design



We can all remember that iconic photograph of astronaut Buzz Aldrin on the moon. An image of sheer vulnerability and isolation.

A fragile human augmented and life-supported by technologies that did not exist a few short years earlier.

In fact, just 8 years earlier in 1961 when Kennedy made his moon-shot statement, the bureaucrats cautioned him that the technology and the materials did not even exist to make this happen.

But it took less than 10 years to put a man on the moon.

NDIS has been going for 7 years.

NDIS and NASA are both complex servicing ecosystems centred around fragile humans.

If we think that over a 10 year period, the NDIS expenditure will be $250 billion, the scale of the expenditure is comparable.

The scale of the ambition is equally momentous.

And the scale of the market opportunities for new innovations and spin-offs is far reaching.

And that image of Buzz Aldrin is the epitome of co-design - or human centred concurrent engineering.

Yet some people would have us believe that human centred co-design is a recent trend to do with apps and websites.

Design and Decision Making

And in these complex servicing systems, there are far reaching lessons on design and leadership, to be drawn from the catastrophic disasters NASA has suffered.

These two photos – the initial flight testing of the Space Shuttle on top of a jumbo jet and the Challenger disaster – illustrate the impact of politics on design and decision making.

And how initial concepts are challenged and changed through co-design. I'll come back to this.

So from this, my experience, perspective and approach is the human experience in complex servicing systems.

And how the human experience is the most critical determinant in service design.

Scene Setting ~ Confusopoly

The 2011 Productivity Commission Report into Disability Care and Support, described the discrimination and heartache that people with disability and their families suffer in trying to find and understand bureaucratic information; and then having to repeatedly provide information over and over again.

The PC Report referred to the words of a family describing their experience of this as "*confusopoly".*

> "...we were very much left to navigate the maze of disability life by ourselves... the *confusopoly* added anxiety and pressure to an already extremely stressful situation..."

And this is why human rights and co-design was seen in the NDIS technology business case – and must continue to be seen – as THE determinant of design.

This is fundamentally about the human experience of people with disability – and their families - in all situations.

Without understanding the human experience and building new capability through co-design, the costs for the NDIS would escalate and the operational performance of the scheme would be impacted.

Let's see how that plays out.

Human Right of Expression ~ the Design Determinant

The UN Convention on the Rights of Persons with Disabilities is remarkable drafting because it pushes innovation into the realms of each person's individual expression of their humanity.

It calls out the paternalistic view of treating people with disabilities as "*objects of charity*" to "*subjects with rights*" based on informed consent.

It defines the *right of freedom of expression and access to information*...

...by accepting and facilitating "*augmentative and alternative communication*" ...

...so that people with disability can "*receive and impart information and ideas on an equal basis*...".

There, in the UN Convention are the design determinants.

So the Convention clearly was targeting the systemic discrimination so aptly described by that family as "confusopoly".

And here is a snap-shot of the reality of the experience of dealing with government, healthcare organisations and the NDIS.

Ranging from just plain difficult to frightening and isolating.

Letters get sent to people who physically can't open them. Or who cannot understand the bureaucratic language because of functional illiteracy or cognitive disability.

Letters, forms and brochures point to the website which is not searchable; to the portal which does not meet the communication and accessibility needs of a great many people; and call centres which cannot meet the needs of people who are non-verbal or have cognitive impairment.

Many people with psychosocial disability or cognitive disability find it traumatising to call the call centre, even the prospect of doing so.

Modelling was done on this – not just the volumes, but the human experience that drives the volumes.

Participants, “Tier 2” people, families, support networks and the disability providers, all seek the same information and answers to their questions.

Forty percent of the questions asked are the same questions, just asked in lots of different ways and not in government speak.

This forty percent figure is a common and known factor in the call centre industry.

The call volumes are a function of the NDIS complexity, the search for contextual information, and the NDIS participant demographics.

The right of freedom of expression and access to information in context and on an equal basis, as expressed in the Convention, is not the reality for most people. Quite the opposite.

Notwithstanding the massive investments, this is a struggling industrial model in all servicing settings.

And this was emphasised in the 2011 PC Report that a different result would not come from the continuation of the same failing approaches.

We are at a Copernican Moment.

Contemporaneously, the foundations of the Internet are changing. We now have the emergence of the “metaverse”, where the Internet is just one part of persistent shared connected virtual spaces.

And that is why in 2015 in Boston, I met with Sir Tim Berners-Lee the creator of the world-wide-web, to discuss the concept of Nadia and our co-design approach - and to understand more about his work on the human accessible web and his proposal on the individual’s control of their own data.

The real challenge for society was/is, how could we make the web itself more human? In fact, human-like and naturally conversational.

Nadia Innovation Supporting Human Rights

Given the human rights impact of confusopoly, the Nadia innovation had one clear goal in support of the human rights of people with disability:

...*to achieve natural empathetic contextual conversations regardless of ability or language*.

What was started as a human rights challenge in Australia and driven by people with disability, would go on to benefit all people. Truly universal design.

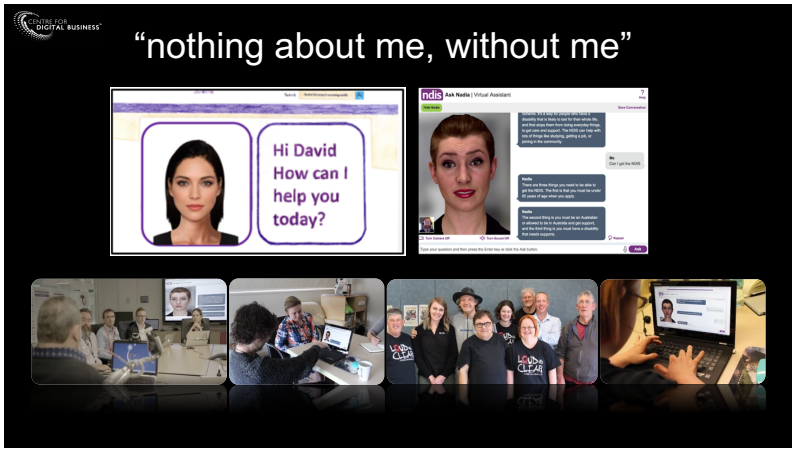
Co-Design ~ Nothing About Me, Without Me

So how could it be that people with disabilities, including those with an intellectual disability, could receive and impart information in their own context, and independently?

Had anyone ever asked or involved them? Had anyone ever acknowledged that the unique insights, skills and experience of people with disability could be imbedded as determinants of design?

And that these new design determinants could quickly become mainstream universal design and benefit everyone?

Nadia was grounded in human rights and we used that to prise open design processes that, for a long time, had effectively excluded people with disability.



Led by Sean, an outstanding entrepreneur running his own technology company, a quadriplegic.

Sven, a deafblind colleague doing a PhD in haptic communication, now continuing his ground-breaking research overseas.

Sam, a disability advocate, human rights advisor and media commentator, running the biggest social media disability community.

Chris, a young man with cerebral palsy, who is a video editor, an Apple ambassador, and collaborating with NASA on the use of the Apple Switch in astronauts gloves. Astronauts fully suited up have limited movement of their hands.

A community network of people with intellectual disability supported by the psychology faculty at the University of the Sunshine Coast.

And many, many hundreds of other people.

The image on the left is a co-designed sketch of what people with disability imagined; drawn on paper and coloured with crayons well before any of the technologies were brought together.

The experience depicted in this sketch, was that people did not want to deal with confusing websites or call centres. They simply wanted to have a face to face conversation and not necessarily with another

human person who might be impatient, judgmental or not even available.

This was many months before the Nadia avatar face was identified: the face in the sketch was a composite face whose features were chosen through co-design.

Next to the sketched image is the final co-designed and tested Nadia interface.

University psychology faculty led the co-design with people with intellectual disability, so that the words, expressions, conversational tempo and personality was empathetic and natural.

Shortly, I'll talk more about new roles and jobs, but I'd like to emphasise here the increasingly important and pre-eminent role of psychologists in co-design. A pre-eminence in design beyond business analysts, architects, and technologists.

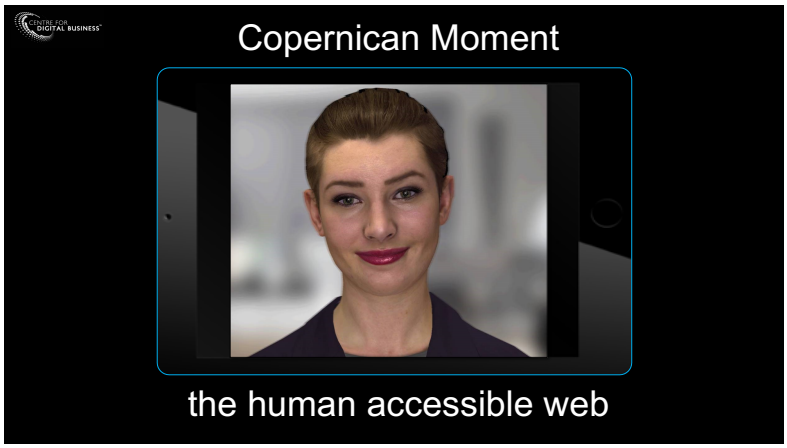
At one co-design session with the intellectual disability network, a lady commented that they are usually only asked if they would like to go to the mall or go bowling. Now she said, we are asked if we would like to help design the avatar.

Importantly, this supported co-design process ensured that information conveyed through contextual conversations was understood by people who are functionally illiterate and people with intellectual disability.

The natural language model and conversation design was a bounded system, meaning that unlike Siri or Alexa, Nadia would not be released into the general population to answer questions on any topic. And it could not learn racist or bad things.

Context matters.

The Copernican Moment: The Human Accessible Web



For the first time, instead of *people having to adapt to systems* – this was a vision to have *systems adapt to people* and so go some way to achieving the objectives of the Convention.

This was not a simple Q&A chatbot – but an embodied conversational human-like system able to determine intent from a corpus of thousands of elements and natural language expressions and gestures.

Most people even in the general population don't seek information via perfectly crafted questions using correct bureaucratic terminology.

For example, most people don't use the word "eligibility". And people with intellectual disability would simply say "how do I get the money...?"

In another example, a young man with Down Syndrome in a conversation with Nadia, stated "I like to dance". From this statement, the Nadia system was able to determine the "intent" of his statement and responded in a simple clear dialogue that the NDIS can fund dance lessons if that was something he would like to do.

So "intents" and "context" are the foundations of the Nadia dialogue model and corpus. That is, her brain.

Nadia was designed and fully tested for lip-reading – so that hearing impaired people could participate in a supportive and natural conversation with others.

It was envisaged that haptics would eventually enable communication with people who are deafblind and for this conversation to occur in parallel formats – such as haptic and spoken – so that a deafblind person would have a choice to interact with Nadia together with their family.

Co-design had also envisaged that a person with motor neuron disease and could only communicate with their brain activity via a NeuroSwitch – that this NeuroSwitch input could be transmitted and de-coded, with the digital human responding with a natural empathetic spoken response.

This design direction was informed by the real life case study of Janet, the first NDIS participant to be funded for a NeuroSwitch.

The augmentative interface concepts involving haptics and brain activity interfacing with the embodied AI digital human Nadia – attracted interest from the Palo Alto Research Centre (PARC) in Silicon Valley.

And all this matters because these are the many ways people communicate.

One size doesn't fit all. In fact...it fits no-one.

During another co-design session, two young mothers who both had children with disability, were explaining what their everyday was like. One of the mothers, Anne, was holding a letter with a lot of codes and reference numbers on it – referring to the services and payments made.

Anne explained that she was terrified of doing something wrong – terrified that a payment would be stopped – but the only time she could go online was 2am when all her children were asleep.

The call centre was not opened at 2am when Anne needed it. She couldn't navigate or even search the website. She broke down explaining that she didn't even know the words to use to search.

So, while the call centres volumes escalated as predicted, there is also a significant and growing unmet demand. Outsourcing does not address this.

Uniquely, co-design combined with artificial intelligence create new servicing models not otherwise possible.

The November 2020 Report of the Aged Care Industry Information Technology Council (ACIITC), describes the case study of the strategic partnership between Feros Care and Google in the integration of the AI based Google Assistant voice-command platform in homecare services.

Two months after its introduction, calls to the phone-based Contact Centre had *reduced* by 85%.

As I mentioned previously, similar modelling was done for the Nadia omni-channel capability.

The important point here is that these digital services do not necessarily require a computer or tablet to be used.

By integrating these technologies into normal everyday life activities, accessibility becomes universal and contextual.

So the mental model of portals, websites and call centres can and must change.

What was also entirely possible then – and included into the Nadia design roadmap – was an object recognition capability. What this would mean in this instance, would be for Anne to hold her letter up to the webcam and Nadia would simply explain what the letter was.

And the horror of filling in forms must be consigned as a relic of history.

Through co-design, people with disability imagined a different experience: a conversation with a digital human to replace the whole concept of forms.

And while there was much interest in the Nadia face, this would be just one persona.

The autism community spoke about a different persona: perhaps a cartoon character or a superhero.

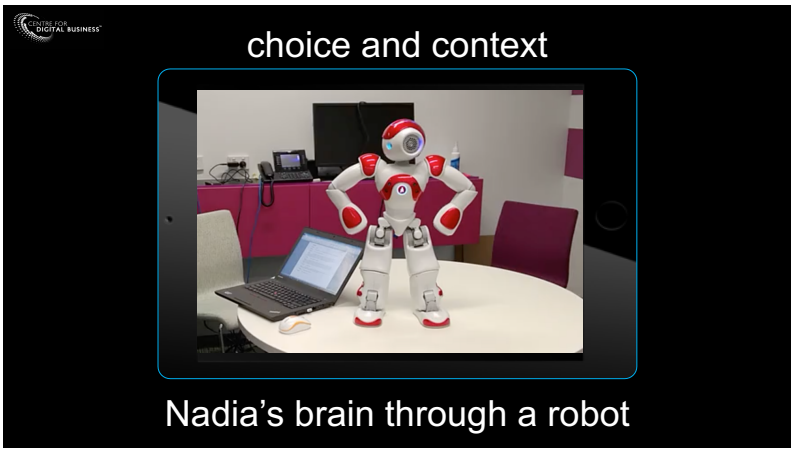
And eventually there would be other personas providing choice to Indigenous and Culturally and Linguistically Diverse (CALD) communities.

Contextual and co-designed. The essence of human rights.

Effectively, the Nadia concept was a framework whereby knowledge could be conveyed via natural language conversations in context to the community served.

That is, giving effect to the UN Convention.

Choice and Context: Conversations Across Form Factors



From the initiating business case, Nadia was to be omni-channel, co-designed to have a presence in different forms across persistent shared connected virtual spaces.

This means that the corpus and language, co-designed and developed to answer 10,000 questions could support natural conversational interactions across form factors and interfaces.

So here we see the Nadia brain enabling a conversational interaction with a robot, in this case the IBM “Pepper” robot.

Immersive Environment for NDIS Marketplace

As an omni-channel capability, Nadia was also designed to have a presence in an immersive environment such as Second Life.

And the reason for this is that immersive gaming environments have been shown to be immensely beneficial for social engagement and capacity building.

People with disability are avid gamers. This is an environment they know; they say they can be whoever they like and are not judged.

And their desire and their idea was to be where they are comfortable.

This would be the NDIS Second Life emarket environment. Where Nadia would have a presence. Where people with disability could *choose* to have their own avatars and act as connectors and mentors...helping one another.

In a session where I presented this, in Geelong with Deakin University, a father came up to me afterwards with tears in his eyes. He said that for his teenage son, who is autistic, that this is his

world. He knows this world and in this environment, he would be able to help himself, engage with and understand all the NDIS market information in a different way.

So instead of a static catalogue of services and prices – an immersive market environment presents that information in an intelligent, interactive and contextual way.

Extreme conditions as a catalyst for disruptive innovation.

Virtual Worlds: Any time, Any Place, Any Body

And this is already happening at the US Veterans Affairs using virtual world market-place environments with avatars, providing rehab support to veterans who are amputees.

Digital humans such as SimCoach have been used for many years in the US in mental health settings, providing rehab support to veterans and service personnel suffering PTSD, and their families.

As a veteran family, I ask, why are these not in use in Australia?

Clinical peer reviewed formal evaluations have demonstrated the effectiveness of avatars and virtual worlds such as Second Life in the provision of services to people with disability including remote rehabilitation services of some profoundly challenging conditions.

Second Life market-places and immersive virtual platforms are of leviathan dimensions.

The online games industry is expected to reach *$300 billion by 2025.*

So why couldn't the NDIS emarket exist in Second Life?

This is an enormous global community and virtual global market too big to ignore – or to not actively run after.

GO TO PART TWO