Digital lifetime of a child born today

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Frances Foster-Thorpe

I join you from both a futures unit in New South Wales and a national team that's focused on how to bring together data from across Australia's governments to improve outcomes for people with disabilities. Today, I'll focus first on the digital life of the child from the perspective of the work that is currently underway in governments to improve the data that would be available for different phases of the child's life. Looking towards 2050, different efforts will need to be made to respond to the expectations that governments are hearing from communities.

For the first nine years of the life of a child who is lucky enough to be born in Australia today, the focus for governments is making sure that data is collected and then used in a way that connects the child and their family to supports that they need to thrive. There are so many potential ways that data and digital systems could be used, it seems helpful to break this down into three key information needs that we will work towards in government.

The first is that data is made available to those working directly with children and to parents, families, caregivers, in order that they can more accurately assess a child's needs. Early on, that information might be available to say, nurses and parents to help assess the child's development and whether they're hitting milestones and then perhaps later to an early educator or teacher in kindergarten and Year 1 to see how they are progressing at preschool and school. Anyone who's had a child born into their family in the last 10 years would know just how extensive the information is about the milestones and the micro milestones that each child is now expected to reach.

The second information need is data that's available to the system responsible for providing services and supports to a child and to their families so that they can see whether there's a match between those needs and the steps available. This question isn't just about the service available in the area where a child and their family live. It involves much more nuanced questions to determine whether that service is appropriate to that child's needs. So if a child has a particular type of disability, for example autism, is there a service available that's inclusive and specialist to the particular needs of that child? There's also a need for public services to understand how children and families are making their way through different systems. This requires what we often refer to as pathways analysis.

And the third information need is making data available to those analysing and researching the evidence base about how to best meet the needs of a child and

their family. This is about connecting needs, services, supports and funding to the outcomes that a child, or cohort of children, can achieve.

A child born today will benefit from the much better understanding that we've obtained globally about the power of early intervention to change pathways that children are on. This is not just about government services — although I mostly think about data in those terms — it's also, crucially, about what I call informal support. This includes supports that come from family and community or supports that a family might privately pay for, as well as the value for a child of being born into an inclusive community or a democracy. Although these are more intangible things, they are really important to life outcomes. Even though we have learnt a great deal about early intervention over recent decades, I think governments come from the perspective, as do most researchers in the sector, that there is so much more to learn; particularly where children have specific needs.

For example, a child born with a particular developmental delay in a culturally diverse family. What are their particular needs? I'm focusing on the rich insights that can come from linking data from service systems and from survey data, without identifying any individual child. Government data is often subject to privacy-preserving and de-identification techniques. This is about understanding the particularities of how children and different cohorts of children move through pathways in life. There are also data systems that identify particular children and families, and they're really important to things like child protection outcomes. Australian governments have done lots of work over the past five to 10

years, to really improve those data systems that support the needs I talked about.

If this child is born in about half of Australian states or territories, they are likely to be born into a jurisdiction that has the kind of data linkage that I was talking about to some extent. But overall, it will be patchy. In the other half, they will not have access to all the service systems that are serving them. Nowhere is there really high-quality, nationally linked data. Australia is comparatively behind in the way that governments can access data systems to inform their own services and have provided access to others, such as researchers or those that provide services, as well as individuals.

We're behind comparable countries like New Zealand, the United Kingdom and Canada, basically, because we have an unusual federal split of who funds different services. Not only are we a federation, with many coordination challenges, but we're a federation where key services provided to children and families are provided across different levels of government. If you think about the first two months of this child's life, they're likely to be born into a hospital system provided by a state government. But when they go home, they'll be serviced by community nurses, also probably provided by a state government, but potentially born into an Aboriginal community, perhaps by a national Aboriginal medical service provider that will then go to a GP.

Fortunately for the child born today, they are born into a country that is massively accelerating its efforts to provide the kind of data systems that I've spoken about today. But I wanted to look forward to when the child is a teenager and then a young adult, and point out expectations that we're hearing from communities. One is that these

information systems are not just the governments'. They are also for people who are making decisions about their own lives. It's not just a one-way transfer of data that governments hold, but it also could enable a rich conversation about the information that communities have about their own outcomes and what's important to them. Also, communities now demand to have a voice in how the data is being used. And we really see this, particularly in the Closing the Gap agreement recently signed by governments, where there's a commitment to sharing much more data, but also a commitment to sharing decision-making about the data.

Sue Bennett

By way of introduction, I'm going to start a story; the story of a child born today and what they're likely to experience as they grow up surrounded by technology. It's clear to all of us that a baby born today is born into an increasingly digital world. For many decades, new innovations in digital technologies have been changing the ways we live our lives, from the ways we work and learn, to the ways we communicate, the ways we socialise, the way we interact with government services such as education and health, and the ways we spend our leisure time. We were well aware of this before COVID, but perhaps we're even more aware of it now. Technology has enabled many of us to learn and work safely from home, to maintain contact with our families, friends and communities, order essentials and other things online, all while being restricted from our usual in-person activities. Through information provision across the internet contact-tracing apps, we've been able to manage some of the risks of the pandemic. Health professionals who've been able to provide

care remotely have done so through the help of technology.

Although we've seen some of the downsides, such as the spread of misinformation, technology has been vital in helping us get through this so far.

So, what now for the 800 or so babies who will be born today in Australia? Well, although we might say those babies are just coming into the world for the first time now, most of them already have a digital footprint.

That footprint will have begun in a number of ways. The most familiar one is an ultrasound photo shared through social media, together with accompanying comments from family and friends. Perhaps parents used a pregnancy app to track progress in anticipation of today, and even before that, parents might have used a fertility app to help them. They can save each interaction on social media or with an app producing data. Some of that data is information that we've entered ourselves — numbers, words, images — and some of that data is automatically generated, say, from settings such as locations and time stamps.

All this data can be analysed and used in real time or cumulatively, and it can be bundled in new and unexpected ways. It can be used to deliver information such as targeted advertising or to make recommendations to individuals, and it can be used to build profiles that power the algorithms and models that were mentioned earlier. And it can be sold on to third parties, and all of this before Day 1 in the lives of babies born today.

What might we expect through the next five, 10, 15 years and beyond? There will be much more sharing of photos and videos, and real-time calls online to stay in touch. As young children grow and explore

the world, touch-screen technologies will become increasingly part of their lives. They'll be playing games and consuming and creating content through smartphones and tablets. As homes become smart homes, households are purchasing voice-activated smart devices that respond to our requests.

A great recent example you might have seen in the media was of a family who discovered that their young child was having conversations with their smart speaker. Add internet-enabled toys: including, say, internet-connected teddy bears that can playback sounds recorded on a smartphone; figurines with motion sensors and face recognition that become part of gameplay; and programmable robots from the simple to the sophisticated.

And now, as we move our attention beyond the home, early childhood education and care services are using technology to connect children, families, carers, educators and other professionals supporting children. These are online platforms allowing communication and sharing of information. Health services and health records are becoming increasingly digitised in a similar way, with clinics and services collecting, storing and sharing information from the earliest stages of a child's life. And as a child grows older, this continued recording, generating, storing and sharing of data will occur across schooling through the official platforms for learning and records of assessment through homework and education apps. It expands through health-monitoring apps like wearable devices that monitor physical activity and nutrition and manage medical conditions.

Over time, with growing independence, babies born today will be making their own choices about engaging with technologies that we know about now. And whatever technologies come next, I'll stop here with the description because I'm sure we'll all have a picture in our minds about the lives ahead for these babies.

I'll leave us to ponder some of the big questions. How can we make the most of the power of technology and the data generated to make our lives better? How can we head off some of the perils that we're already alert to and be ready to face new ones? How can we balance protections, especially for the most vulnerable in our society, with personal choice and freedoms?

Discussion

Prof Oppermann: It's challenging for us to get away from the topic of data because this is how we see the world around us; also something we're increasingly generating as we use online services. Sue, you raised the point about an internet-enabled teddy bear, which seems slightly mind-blowing. A question from our audience is how might we effectively coordinate and scale co-design of our digital technologies? If we are constantly keeping people-centred design, people-focused outcomes at the heart of everything we do, that should be a defence or protection against doing the wrong thing, inadvertently doing things which are not for the net benefit of people in the long term, but scaling that people-centred design is challenging. Sue, how would you effectively go about coordinating and scaling co-design for digital technologies?

SB: Well, we do very little co-design of technology with the people who will end up using it. And if we're talking about children ... sometimes people have a deficit view and think children don't really know what's good for them, they don't know what they

need or want. A lot of products that are created for children are created by people who have not even worked with children; who often produce something that has not been tested on children and who then don't have an iterative cycle of obtaining and using feedback to improve the relevant technologies. As we domesticate technology, we often change the way that a design is envisaged. So, I think we have to fundamentally change our mindset and build it into the model of interaction. With that will come a cost. It'll cost in time and additional work, but it's overdue. Absolutely.

Prof Oppermann: I love the expression of "domesticating technologies." Frances, there are more questions coming in. I'm going to offer you the choice of either talking about co-design or about the importance of language and how the semantics that we use really matter.

FF-T: Maybe. I'll try to answer both, again talking on behalf of governments. Any data, government data and digital initiatives, need to start with co-designing what it is that we're trying to produce in terms of what we'd call insight tools. For example, we produced the National Disability Data Asset Pilot even though we didn't yet have all of the data to power those tools, and what we heard from the people with disability that we co-designed with (although I hasten to add that were not children and young people) was that they didn't just want a bunch of data insights about them put online for others to read. They wanted themselves to see the insights that can be generated by the kinds of data that government holds.

They wanted to understand the stories that people living with disability hold, to understand: Do those data insights resonate in my life or not? And what's the missing part of our picture? Increasingly, communities are saying it's not just about data, it's about information, knowledge and stories and bridging the quite antiquated idea that you have quantitative insights and you have qualitative insights; knowing that now you can have insights that are developed through a much more sophisticated dialogue between the quantitative and qualitative data. That can be really effectively done through designing the technology whereby we share those insights.

Prof Oppermann: Now I asked our first speakers, Hugh and Cathy, when will we reach the point that we actually know and understand how to appropriately use data, acknowledging biases, acknowledging potential harms, acknowledging all of the challenges. Hugh gave a very strong answer around bias and the skills that statisticians developed around bias. But Sue raised the point about internet-connected teddy bears where there are data sets being generated, interactions being analysed, which we wouldn't otherwise have expected.

Frances, over to you: Where do you think we are in terms of our ability to handle data appropriately? When do we get to the point where we know how to use data safely?

FF-T: Oh, that is a tricky one. I think we use data very safely within governments where we have had a lot of experience with data within a particular service system … where we've been using it for decades. And we're very aware of the limitations of that data. But what I think Hugh and Cathy were talking about is much more sophisticated, linked, and integrated data sets and much more sophisticated methodologies to use that data. We should be open in saying we're relatively early in that process. And

that's not just about understanding the data itself, it's also about that process of triangulation I referred to; of saying — even once you understand the data very well — that's only part of the picture. What are your other sources of insights? So I think that governments have heard those expectations from communities, and we are busily figuring out what are the systems that need to be in place to systematically learn the power and the limits of data and the insights that we should be developing.

Prof Oppermann: And now to the parallel question of appropriate use. It may seem innocuous to have a teddy bear connected to the internet, but there are some real challenges there. How do we reframe the conversation around what we should be doing? How do we tell what is appropriate use?

SB: We need to have much greater transparency around the data collected and how it's used. Most of us are aware that data is being collected about us and it's being used in particular ways, but it's actually invisible to us. It's hidden, it's obscured. And that's deliberate because data is a valuable, commercial commodity. But that value is lost to us because we're engaged in relationships where we're required or expected to give it away in exchange for a service or product. When can we have a level of ownership over our data (even as we've given it away), and have some control and some say in how it's used? Inherent in providing people with a data-driven service is actually understanding what they want and allowing them to bring their interpretations to say: "Actually, you've got this bit wrong" or "No, I don't want you to use this and I don't want you to use these things together."

It strikes me that in so much of our lives, we're giving away something that's incred-ibly valuable to us, and I wonder how we can put some of the control back and build some new social norms about how we expect not just government but also commercial providers to engage with our data in responsible ways. These are moral and ethical questions and dialogues that we really need to have as a society.

Prof Oppermann: Frances, let me ask you about the moral and ethical dialogue. Is there a way that we can fast-forward and build those frameworks so that we can build our touchstone for appropriate use of data?

FF-T: I think we owe a great deal to the thinking that Aboriginal communities have done about institutionalising that dialogue. I'd say we should absolutely have frameworks. But what matters to everyone is that those frameworks are used every day and that the dialogue can evolve theses over time that have community trust and social licence. We are early on in building this understanding, but I think that the Closing the Gap national agreement that was signed by governments in 2021 is very interesting in that it agrees to shared decision-making about using data where there is that institutionalised dialogue between a given community or organisation and government. I should say that it is much more difficult for governments to handle data about individuals because of the way that data systems are configured; it is not a matter of just saying, "I'd like to opt out." That's almost a separate problem set. But that idea of institutionalising dialogue about acceptable uses of data is where participatory data stewardship thinking or data sovereignty thinking being developed by communities and in dialogue with governments.

Prof Oppermann: I just want to ask you one question. I really want you to dig deep and

think about 2050. What are the most important topics that we're discussing about the life of today's child in 2050?

SB: Well, I think there's one word: inequalities. Despite all of the advances that we've made, although some inequalities fade away, some persist, new ones arise and continue. So I think we need to look at how those inequalities are arising and we need to have our eyes very much on inclusion.

Prof Oppermann: Frances, 2050 — what's the most important topic we're discussing?

FF-T: How are we empowering a 31-year-old now, a young adult or a mature adult, to not make decisions just about their own lives, but to engage with their communities and as a citizen, about the issues that matter to them?