

TRANSCRIPT OF PROCEEDINGS

THE HON JULIA GILLARD AC, Commissioner

THE ROYAL COMMISSION INTO EARLY CHILD EDUCATION AND CARE

MONDAY, 27 MARCH 2023

AT 2.00 PM

This transcript is intended as a guide only and as an aide memoire with respect to the audio-visual record, which constitutes the official record of the hearing on 27 March 2023

SARAH ATTAR, Counsel Assisting

< HEARING RESUMED AT 2.00PM

COMMISSIONER

So we are back for our afternoon session in which we will take evidence from two witnesses.

So I will hand over to Counsel Assisting.

COUNSEL ASSISTING

Thank you, Commissioner. I call Professor Katina D'Onise

< PROFESSOR KATINA D'ONISE AFFIRMED

COUNSEL ASSISTING

Professor, I understand you have a medical degree as your initial training.

PROFESSOR D'ONISE

Yes, that's correct.

COUNSEL ASSISTING

And you have been a consultant in public health medicine since about 2008, is that correct?

PROFESSOR D'ONISE

Yes, that's correct.

COUNSEL ASSISTING

I understand you completed a PhD in epidemiology in 2011.

PROFESSOR D'ONISE

Yes.

COUNSEL ASSISTING

And you've previously undertaken work within communicable disease control, Aboriginal health and academia. Is that right?

PROFESSOR D'ONISE

That's correct.

COUNSEL ASSISTING

At the moment you're the Executive Director of the Prevention and Population Health part of Wellbeing SA, is that right?

PROFESSOR D'ONISE

That's correct.

COUNSEL ASSISTING

Can you give us a brief description as to what Prevention and Population Health does and what Wellbeing SA, what role that undertakes within government?

PROFESSOR D'ONISE

Sure. So Wellbeing SA is a prevention agency of government. So it's a public health prevention, with a focus mostly on chronic disease and injury prevention, mostly at that primary prevention end of the spectrum, but a bit of secondary prevention as well. So, within my directorate is health promotion branch. So that's the policy programmatic part of that equation. We have secondary prevention, which is about cancer screening and increasing participation in the cancer screening programs. And then we have epidemiology, which is where we house a number of statutory data collections and other collections that inform us on chronic disease and injury for south Australia, as well as an analysis team. We have some developers as well. So that's a kind of a rounded if you like information system that supports the health promotion, um, and secondary prevention functions in Wellbeing SA.

COUNSEL ASSISTING

And as part of your role I understand that you have had a vast amount of experience in developing and maintaining data systems. Is that correct?

PROFESSOR D'ONISE

Yes, that's correct. So the epidemiology part, which I've been involved in for many years, um, yeah, so we've both, adapted, improved, maintained existing data systems, because we have some that stretch back to 1970, as well as we've, uh, brought on whole new data systems in that time

COUNSEL ASSISTING

When we use the term data system at its base, are we talking about a collection of information as a very, you know, simplistic explanation?

PROFESSOR D'ONISE

Yeah. So, what I mean by data system is basically every aspect that we require from end to end in that system, such that we have high quality data that we can rely on to use over time. I don't know if you want me to go into a bit of more now?

COUNSEL ASSISTING

We'll come back to the perhaps ingredients as to, in, in your experience make for a strong data system, but I should clarify, first of all, that, you're not here today to speak particularly on behalf of your department; we're asking you to draw upon your expertise, about the nature of public health data and, and how we might learn from that. So we're certainly not asking you today to speak on behalf of, of particular government data implementation. But I understand that at the moment, you're also the custodian of a number of what we call statutory data systems. Is that correct?

PROFESSOR D'ONISE

Yes, that's correct. So within my role in Wellbeing SA and, um, we do have a Director of Epidemiology who reports through to me, but I maintain that role of being custodian of the collections. So that basically means, taking the legislation as it stands as relevant to that data system and looking at other matters like ethics and other considerations as to whether and how we will release data and for what purpose,

COUNSEL ASSISTING

One of those data systems over which you're custodian is the suicide registry?,

PROFESSOR D'ONISE

Yes, that's one of them.

COUNSEL ASSISTING

And you've mentioned some work within cancer and the cancer registry. Is that another example?

PROFESSOR D'ONISE

Yes, that's another example.

COUNSEL ASSISTING

If we come back to data systems and as you've mentioned, that's perhaps simplistic to look at it as just containing information because, as you've touched upon, good data systems, if I understand correctly are ones that can properly accommodate the purpose by which the data

is gathered for, and that ranges right through to proper rules about who can access it. Is that a very broad summary?

PROFESSOR D'ONISE

Yes. Yes.

COUNSEL ASSISTING

If we stick with health for the moment, how important is good quality data collection in public health?

PROFESSOR D'ONISE

Oh, it's a foundational part of the system. We have now decades of when data have been collected for particular purposes in the health system, it drives policy planning. We use it for research, evaluation and safety and quality. So depending on which part of the health system we're talking about, but you know, there, there are a large number of purposes, but I guess the most important part, it is a, it is a foundation to healthcare delivery, but also from a, a public health perspective, I would consider it one of the critical pillars of public health.

COUNSEL ASSISTING

You were here, I believe for the session before lunch, when we heard from, Ms. Beck and Ms. Hawkins about the Child Family Support System. Is that a good example by which we might talk through today how you design and implement a system such as this, from the ground up?

PROFESSOR D'ONISE

Yes, it is. I mean, I guess one of the things about when we think about it from a public health perspective, so I'll keep returning to that frame, we think about the universal. So what we saw this morning was shifted at that really probably more secondary tertiary end leaning more towards the tertiary, but what we would be looking at is also including primary prevention. So that's about all those kids who are doing well and we want to help remain, you know, to do well, and their families, through to identifying kids who, who are at risk, what do we need to do there? And then there's kids who, who have got risk and what do we need to do there to mitigate the risk? So that's how we kind of think about it as primary, secondary tertiary, but we do think about it in its entirety.

COUNSEL ASSISTING

Perhaps I asked the question confusingly. Can we look at the Child and Family Support System and see within it what you are going to help us understand today in terms of some of those key elements of a, of a good and strong data system,

PROFESSOR D'ONISE

Certainly.

COUNSEL ASSISTING

And we might from time to time refer back to that, to give us some, some practical examples. We heard this morning that one of the fundamental changes that, that new system was able to bring in was the linking of already held data sets.

PROFESSOR D'ONISE

Yes

COUNSEL ASSISTING

How significant is that in your view to be embedded within, systems of, of data collection more broadly; that they interact with other known data?

PROFESSOR D'ONISE

I think it's a critical element. I mean, even just from practical, a practical perspective, we can't really have duplication of data systems across government, for example. So we really want to be efficient. We only want things collected once by the right people who have the right expertise to collect that kind of data. But that then means that, you know, if we are interested in understanding how it intersects, for example, in housing or how it intersects with another area that we bring those data sets together. So yeah, it is, the linkage part is, is absolutely critical. If we didn't have that, for example, within our own systems, we would have to collect information about housing. We would, our collections would become untenable, they'd become unruly, and probably incorrect actually as well because we're outside, we are outside of our primary scope. So if every, everybody keeps to their proper scope, we have all the quality people who know really what should be collected and how, and then we have the opportunity to bring it all together to create the full picture. So yes, data linkage is critical.

COUNSEL ASSISTING

What are some of those other key components that you see as integral to a good data system?

PROFESSOR D'ONISE

So, there are quite a few parts that are integral. One is it really does need to have very clear rules about what is collected by whom, and what, for what purpose. So that, that there is like the kind of foundation to a, a good quality data system. It needs to have all of the sorts of structures within it with regards to what's collected. So that includes matters like standardisation. We need to really make sure that what we are doing is all collecting the very

same thing in the same way. It needs to be comparable to other collections, perhaps other jurisdictions, other countries, so that we can compare ourselves over time. It needs to be timely, at least to the purpose of the system. So for example, if it's a service system, that's obviously an instant type of system vs. the cancer registry, which doesn't need to be instant because we actually measure success in years of life following a cancer diagnosis. So it's a, so you see, they're designed around different timelines. High quality systems also have a series of rules that are applied consistently. So we have staff who know how to do this consistently. We have coding guidelines. So all of these things mean that what we are collecting is basically the same information over time, and has quality assurance activities. So those quality assurance activities will look for error, either in our coding or in the source starter that we've used. And, and I'll just check what else I've got here so I make sure that I've got everything. It needs to be, as complete as possible. Now that again, depends on its purpose, but when we think about the term registry, which is, I guess, where I'm coming from, registry implies a hundred percent ascertainment of all cases and we need to get as close to that as possible because we make, assumptions when we are doing analyses that we actually have the entirety. That's one of the critical, underlying elements. We also need for the data that we want to use it accuracy, it needs to reflect what it, what it is saying it's trying to reflect, and there needs to be rules as to how it is all used and for what purpose and what are the mechanisms to use the data. So, so that we have a proper purpose, the data systems are properly designed around the purpose, and we are following all the agreed rules so that we know that, you know, we're staying within what is, what is acceptable practise.

COUNSEL ASSISTING

We'll unpack all of those concepts if we can. First of all, can I ask you to take us back and explain to us whether there are different options when it comes to, the way in which data system can be structured and by that, I mean, does it have to use legislation or are there different options?

PROFESSOR D'ONISE

Yeah. Yeah. Thank you. So, within the, uh, the government context and public health, again, we do have two frameworks. One is a legislative framework and another is an ethics based framework. It's not possible to collect data in the absence of either of those frameworks. So legislation, there are a variety of mechanisms to achieve this. Most commonly there's some kind of act that either allows for a registry or requires annual reporting to parliament, for example and allows for the, the making of regulations. And it's usually in the regulations where we have those details about who's reporting, what are they reporting, how are the data to be used? So that kind of structure is the basis of the majority of the collections that we have in the epidemiology branch, but using different legislative frameworks, achieving the same outcome,

COUNSEL ASSSITING

And each one tailored, presumably to their purpose and their scope.

PROFESSOR D'ONISE

Yes, certainly. And also, some of these things have evolved over time as well. So, you know, how, how parliament decided to do that 20 years ago vs. now, you know, may be different, but, nevertheless they have the same kind of effect, for data collections. An alternative, approach is through an ethics committee, so a human research ethics committee, and there, so that also works where, because we'd be collecting, so, sorry, I should clarify, I'm really talking here about identified data.

COUNSEL ASSISTING

Okay. Well, perhaps we'll, we'll go back a few steps then and, hopefully we can all reach that, that point with you. We heard some evidence before lunch about, data sets that allow us to draw conclusions at a population level. So data that might come from hospitals that could tell us how many people, were admitted from a particular disease in a particular year, for example. And then we might be able to draw out without identifying those people what they presented for. And we heard that the Child and Family Support System has access to some population level data, and that it now also collects its own data from families, about matters specific and identifiable to them. So is that an illustration of this concept of de-identified data and identified data?

PROFESSOR D'ONISE

It certainly is, but I will make the point that that de-identified data is actually source data identified.

COUNSEL ASSISTING

Correct. Yes.

PROFESSOR D'ONISE

So actually it's all identified data. It's just the end user in the first in the service instance has access to the identified data. In the other instance of the link set, they don't

COUNSEL ASSISTING

Thank you. And when we are talking about these legislative options for establishing a data system, part of those rules that you've mentioned are they rules that will often stipulate, if somebody wants to make an application to make use of data held by a particular agency, what aspects of that data they have access to, and for what purpose and for how long and under what circumstances?

PROFESSOR D'ONISE

Yes.

COUNSEL ASSISTING

And in a lot of cases, is it the case that what is being accessed is that de-identified version of the data? So I might be able to tell that a particular school, for example, had, um, X number of students who didn't attend on X day, but I might not know who they are.

PROFESSOR D'ONISE

Certainly. So I will say that that depends on the purpose of the collection. So for example, in a registry, I can't recall a single time of releasing identified data. But certainly we have, for example, data linkage units, and there is a, there's a proper process of separation of identified data from content data, but don't, you know, that's how we do data linkage through a proper process of separation. So there's no, organisation, for example, that can bring it all together in an identified form. So I will say that where we've joined up government data to a study, a research study where each individual in that study has given expressed written consent that we can link then that, that also occurs and that's clearly identified. But what we're really talking about here is that in the event of having a non individual consent process, yes, it basically is, is shared in a de-identified form. But further to that, we also have principles that data are only shared as the minimum necessary to achieve the outcome. And that happens even if an ethics committee, for example, might decide that, you know, this group can have this level of data as custodians. We will apply that as well as the legislation. And we will look to the absolute minimum necessary required. And we look to de-identify in every aspect, not just by name, but we, we, for example, remove date of birth, if it's not necessary, we could do an age; you know, we don't give postcode information. So we, we take all efforts to reduce to the minimum necessary. That's why as well, people who are custodians of data, need to understand epidemiology because they need to understand, well, what do you actually need to answer that question as opposed to what we've been asked

PROFESSOR D'ONISE

And does that then highlight the importance of having at the base level identified data that is properly collected in a standard fashion that then is, is kept with a proper custodian who can unpick what is required at a bare minimum for somebody to go on and consider and analyse data

PROFESSOR D'ONISE

That's correct.

COUNSEL ASSISTING

In your personal view how important is identified data when it comes to properly putting together a system that can, uh, support a good service delivery?

PROFESSOR D'ONISE

Well, I think it's foundational actually. So, the identified data allows us even just from the perspective of a singular statutory collection. And remember I talked about the need for a hundred percent case as attainment will oftentimes, the reporting systems, even if they're very good reporting systems, won't be perfect because, you know, things can happen across systems. So we develop, um, we use that identified data, for example, to link to other systems where it will help us to find if we have gaps. So, that that would be a normal, that's a normal practise within a registry. So we're always looking for, making our way to a hundred percent. Another aspect of a system from a quality perspective, as to why we need data, for example, if we wanted to look at a complication of a surgical procedure, if we were to rely entirely on an original, receipt of information about the surgical procedure, we would naturally be missing any subsequent, you know, 2, 3, 4 weeks later complication of that surgical procedure. But if we have identified data, we can link to our other health systems. We can identify that later complication. And now we have a complete collection if we were to report on complications, as opposed to an incomplete and biased collection, if we only were at the time of reporting. So there's, yeah, the quality and ascertain part of our data systems fundamentally rely on identified data. Another example is, where we want to improve the Aboriginal identification in our systems. We know some of the source systems might be missing information on whether a person identifies as Aboriginal or Torres Strait Islander or both and we can use other data systems to help us to fill that gap, knowing that it's a really important part of our data systems to collect. So that's a quality ascertain side from a research or use side. The example you've already pointed to with data linkage can only occur with identified data.

COUNSEL ASSISTING

If we stick with a statutory model in terms of a, a database, will that compel provision of data, no matter who you are, for example.

PROFESSOR D'ONISE

Well, yes. I mean that, that it can, yes. So, for example, perhaps one that's, more familiar to people is communicable disease control. People know that if you've got a COVID positive test result, that it was reported. So that is an example of reporting under the Public Health Act, or it could have that could have been under different acts, but nevertheless, if we can just go with a general, example of notification of disease that, it basically compels who will report, what will, what will they report? And it, it goes beyond a government system. So that's public providers, private providers.

PROFESSOR D'ONISE

What are the key benefits in your view to using a legislative model, in terms of implementing and designing a data system?

PROFESSOR D'ONISE

Well, I think that you can't really well, firstly, if I can just start with, when we have legislation, it provides a very clear framework for those of us who are involved in data systems to work with. So through that, we'll understand the purpose of the collection very clearly. We will understand how data can be used and all, and the various aspects that I've already gone through. Then we've always got that legislation to fall back on with, you know, with tricky questions where things are kind of out of the ordinary. Legislation as well is by definition, goes through parliament. So that's a, that's a mechanism for having, well, accountability, if you like to government systems, because it's through parliament often, there's parliamentary reporting. That's another layer of accountability that I think, is important. So I think the fact that legislation very clearly defines what is to be reported is a very helpful part as well. So that means for example, that we wouldn't have different understandings of what cancer means to everybody. So we have, so that's an, obviously an easy example. If we move into the early childhood sector, it gets a little bit more complex, but that, that even, would further require definition. So that we're all spectacularly clear about what are we talking about when we mean this thing is going to now be reported. So that's a helpful, part of legislation.

COUNSEL ASSISTING

One of the participants mentioned before lunch, the importance of, standardisation within the changes that were made to that particular system. In your view, is the importance of those very clear directions as to what must be collected at a minimum by whom and when, so that the same information is being gathered at the same time by qualified people.

PROFESSOR D'ONISE

Yes, absolutely. So we have, some of our registries, for example, have specified schedules where we've even got it, as, you know, absolutely clearly defined what exactly is to be reported into the system. And that is very helpful. If I can just say from an epidemiology perspective, um, because within our cancer registry, which has been in place for decades, we still can do analyses that stretch back to the 1980s to now, because what has been collected is exactly the same thing over time. So it does mean that we can look at well, if there is a change over time, let's say we have more of certain cancer or less of a certain cancer. We can be sure that it's not because we changed the way we did it over time. Now, legislation really does enable that to happen because of these, very clearly defined rules, which I guess I've gone over a few times, but they're, they are absolutely critical. We, we often add to collections, but one of the things that we are loathed to do is change collections over time, because it means that we've lost our, our kind of core trend data over time, which from a public health perspective is critical.

COUNSEL ASSISTING

Can you contrast the statutory framework with the more ethics based option of establishing a data system and perhaps give us an example of one of the latter.

PROFESSOR D'ONISE

So ethics based systems, tend to that not exclusively, but there, for example, used by universities for individual project based work. So, people have to do an application to a human research ethics committee it's considered by the committee, and the committee will approve or not, as the case may be. So, I think, and that does also allow, identified data to be collected. It is trickier from an ethics perspective to have that approved, but it's not impossible. There are mechanisms for it, but ethics committees will invariably require that when there's, that sort of identified data collection, that there is a consent process and so that means that for an individual, they will go through with the practitioner, whoever it might be, the details of why data are collected, you know, how they used. There's a proper process of consent, the person signs that's recorded and then that person enters into the study. In a, in a statutory collection, basically a hundred percent of cases as defined in the legislation will end up in the legislation, but in an ethics based, firstly there's obviously the resource implications of consent but secondly, not everybody will consent. So, we naturally won't have a hundred percent of cases in an ethics based collection, which I will say is not consequential for most research studies, that's, that doesn't reduce their quality. But, one of the things about consent based processes is certain people are more likely to consent into a research project than our others. If those certain people are kind of patterned, if you like, what we can end up doing in our collections, if we are aiming for a hundred percent, is we are basically systematically knocking out certain types of people from the collection. And so they'll become kind of invisible if you like to the system. So for example, we know that young men are not, you know, are on the lower end of the scale, likely to, uh, agree to participate in a consent based process. But, and if our question relates to young men you know, and risk taking behaviours, for example, we would actually not have a complete collection on which to assess that question because we'd be missing a reasonable proportion of the cohort we were interested in. So one of them basically compels completeness and quality and the other, you can have high quality, but generally won't be complete. The other aspect of ethics processes is that because the decision maker is an research ethics committee, um, you know, these projects are only approved for a period of time. When that time is up, you do need to go back to the ethics committee and seek extension or re-approval, which is not a guaranteed decision. And so if we are really talking about the sorts of systems that we need, you know, for example, in the early childhood space, um, we, that would be exposed to the risk of the whole project halting, from an ethics perspective at each repeat visit of the ethics process.

COUNSEL ASSISTING

And if we come back to your earlier point about starting with the importance or the purpose for which the data is being collected, if it's being collected to support service, delivery, in your view is one method preferable to the other.

PROFESSOR D'ONISE

Well, service delivery should really be a hundred percent, by definition, because we are really offering services. And, and again, as you say, it depends on your purpose. So if we, if what we want out of a service delivery system is just a record of a person's been seen, well, that's a

pretty simple system. And generally there's some sort of legislation that exists that would cover most of that from a government perspective, at least. But if what we want to see is, when a person comes for a service and we are making a referral to a subsequent service, and we want to see: has that person actually made it to that subsequent service; did they get treatment; what is their outcome in the long run - that requires a hundred percent ascertainment and we need to know, and we, and it needs to be identified so that we can see that that person, that individual didn't actually make it to the referral, or they went to, to the refer to get their referral met and they didn't receive a service or for whatever reason, but that absolutely has to be identified because otherwise we wouldn't know where people were. So that, that would be what I would call a quality safety type system, where it's primary purpose is that we're doing high quality care.

COUNSEL ASSISTING

In health it's obviously routine to collect large amounts of relatively personal information. What key, uh, advice probably isn't the right word, but what insights would you give to members of the public who are wary of more extensive data being collected about children, if we centre this now into the early years, and about their families?

PROFESSOR D'ONISE

Yeah, look, I mean, I, I think it's a really, really important matter. And I will say that we take this matter incredibly seriously within our, um, area, for example, with the sorts of collections that we have, I think, there are considerations with data security that are paramount, and we do have very high quality safety systems, within health. I, I can only really speak from a health perspective, but I'm sure that goes broader than the health department. There are also those, legislative structures provide really clear guidance on how we can use data and they make it easier for someone like me to know when it's appropriate and when it's not appropriate, but we follow those rules very carefully. We have other layers as well from a kind of a policy perspective, like a data release guideline. So that takes the legislation and then really is very clear about how we would do data release and in what circumstances, all those rules about de-identifying. If we have a very small number in a data cell, so where someone potentially could identify an individual, we, uh, don't provide the data. So we have all of these ways to, in a way obfuscate. So we, we, we have the detailed data, but what we provide to the user obfuscates, to an extent that it's not possible to identify people. And we have people who are expert in this and we have, so it is something that we put a great deal of consideration into. And I think the other side of it is that people expect that we will use their data well and for a proper purpose. So if a, if a person's had cancer, for example I think it's fair to say that people want to know that we are using that to pro to improve the quality of the service provision, but also to prevent people from getting cancer in the long run. So, I think that it's proper purpose for a public good is absolutely integral to any data collection.

COUNSEL ASSISTING

Can we perhaps illustrate some of the concepts you've been explaining to us by taking an example that we might consider in the early years and that is, if, if consideration was to be

given to a more fulsome and regular child development check, for example, and we wanted to look at implementing and designing a system to help capture that, in your view, would a legislative system allow for more standardised data collection, which is crucial as you've said.

PROFESSOR D'ONISE

Yes, it will. I think as well in the setting of the child development checks, because we have both public and private providers involved in child development checks, that would be an example of one of the, I guess if we're going to, if we needed to have, if there were reasons why you would adopt a legislative system over a different system, one of them is absolutely the fact that it combines public and private data. Otherwise if it was something, for example, that was entirely within the remit of, um, CAFHS in south Australia, that would be an example of where it's already government data. And, you know, you would really have to think about where the legislation was required because it's already held by one agency. The standardisation can happen within the one agency and the reporting happens within the one agency, but where we span outside one agency, we span into the private sector. That's where considerations of legislation come in.

COUNSEL ASSISTING

The Commission knows now from some of the work that has recently gone up on our website, facilitated by Deloitte, that there is a lot of information that's been captured by providers outside of the government that perhaps wasn't widely known within the public sector. Would a statutory framework, as I understand it, then facilitate by, by compelling provision of information by all organisations, whether you're public or private bringing in that information that we might not have had before.

PROFESSOR D'ONISE

Yes, yes.

COUNSEL ASSISTING

Is another benefit that some of these services being offered could be offering a more standardised service amongst different providers, capturing public and private.

PROFESSOR D'ONISE

Yeah, well, I guess if we, if, if we were to look forward and accept that there might be a legislative framework, one of the steps we would take, I mean, apart the first step would be defining the purpose as I've gone over. So once we are clear about the purpose and even the strategy and the, we would also look at things such as what's already been collected. Um, so we would have to really understand what the current status quo was. One of our next steps would be to define, well, what data would be reported. And in my mind, that's defining what do we mean by child development check? So that doesn't necessarily have to be, uh, so it depends how these things are designed. It doesn't have to be prescriptive, as in it check a box,

it could also be minimum standard, for example, that let's say four different checks meet, but what we would need in the collection is the same data items. So we, we would need to look into that. There would need to be stakeholder agreement as to what that would look like. So there would be a process. What have, what have we already got? Where are the gaps? And what have we all agree is the critical information we need to fill that gap, including what, what do we mean when we say we've done a child development check.

COUNSEL ASSISTING

We had a, something of an introductory example of that in the session before lunch, would you agree when, Ms. Beck and Ms. Hawkins took us through that initial research phase and then consulting stakeholders and trying to unpack and unpick what existed and, and what direction that particular agency might, might take. Does that give a sort of tangible example as to what you are describing?

PROFESSOR D'ONISE

Yes, absolutely because, uh, the success of any system really does need to, well, it needs to be useful. It needs not to overburden the reporting as well. So that's a critical aspect. And I will say here that how you design from a technological perspective, the system, also facilitates people being compliant with such legislation. So if it's really easy for people, if, for example, there's an automated flow out of whatever system into this, kind of collection in anything we can do to make it easier for providers is, is what we should be doing. If there's a high burden, then we really risk our ascertainment and our completeness.

COUNSEL ASSISTING

So as part of that, that initial implementation, do I take it from what you've said that thought has to go in right from the start as to who on the ground will be undertaking the collection and how it, it might fit into their other duties to maximise what you've called a hundred percent ascertainment.

PROFESSOR D'ONISE

Yes. And supported by technology, and as well when you, if, if this is a legislative collection and let's say we have regulations, we can't take regulations forward without knowing that we've really got something that is feasible, practical, useful, important and that we have consensus agreement on, well, if not consensus, but majority. Yeah.

COUNSEL ASSISTING

If we go back to this example of, of possibly standardising or developing child development checks, are there other benefits to a legislative system in your view, for example, does it, as well as providing for standardised data collection, do they also help, possibly build in additional sources of material that some people might be capturing, but otherwise aren't known about within the community?

PROFESSOR D'ONISE

Uh...

COUNSEL ASSISTING

I've asked that poorly. Is there, is there potential within a statutory system to be flexible in terms of prescribing a minimum amount of data that might be required, but also allowing it to capture if a particular provider is already asking for or capturing additional data?

PROFESSOR D'ONISE

Yes.

COUNSEL ASSISTING

Can that be complimentary?

PROFESSOR D'ONISE

Absolutely. So there's two parts to that. One is legislation can also include, apart from a core set, which of course, many of these collections would have, can also have data elements that could be mandatory to report, but only if available. We have examples of that for, in our cancer registry, for example, because that recognises that not everyone's going to collect that as part of their core set, but if they had that data, that would be very useful, and important to kind of round off our systems. So we have that model. We also have another model whereby not so much by legislation, but by virtual, the fact that data infrastructure has been built, uh, and, you know, these systems are quite complex and difficult to bring into being. So if, if that collection that has been built on the basis of legislation, can also help a service by having an add-on bit, that means that they can add, you know, they, a particular hospital, for example, might be interested in extended reporting on something beyond the core collection. If that IT system can also help them to collect that data and also report, but only to them, because data systems can be built in such a manner, then it can be also helpful to the provider who's providing data. So I guess really, what I'm talking about here is being helpful and useful, a helpful, useful system, has a greater level of engagement with providers than one that is overburdensome or, you know, collects data that's not necessary or, or what have you. Yeah.

COUNSEL ASSISTING

You mentioned the workforce and other supports that are required to enable these systems to function. What does that workforce comprise of?

PROFESSOR D'ONISE

So it's different in the building of a system in the first instance vs. the ongoing maintenance. When we are building a system from scratch, there's absolutely a need for subject matter

experts as part of that but business analysts are really critical. They're the people who look at, you know, what, what the subject matter experts want, and they create a set of specifications if you like. So that, and it, the clearer they can be about what the system needs to look at, they can then pass it on to the system architects and the developers to actually create that system. That loop with the subject matter experts is very tight, uh, because there needs to be ongoing discussion, problem solving. These things do take a while, and then there has to be testing at the end to make sure that this system actually works. Then we need to include, you know, in the kind of ongoing phase in our world, we would include epidemiologists, because there are always, it's just, it's quite surprising, that even in systems that have been in place for decades, there are always questions to be answered. You know, there might be new developments, for example, in cancer, there's genomics. So that's a question, you know, do we collect, how do we collect, you know, those processes. There's also a role for, obviously, there's a custodian role. There's also a role for ongoing kind of legislation governance overview. So that might be that, well, actually things have changed, perhaps we need to seek changing of the regulations to match whatever the current new issues are. We have coding staff, so the people who will plug the gaps, because there will always be gaps. We try to limit that of course, to the bare minimum, but we know we need a human oversight. Actually computers are not quite there yet to do it without us. And you know, you need managers of the system and then you need the analysts. So then we kind of, now we're moving into the, using the data. They're both extracting data for other people to use, but they're also, um, doing analysis themselves. Now in an ideal world that, there is, absolutely connected with the policy intervention, service arm, whatever, whatever is the, you know, whatever that system is being designed for. That loop needs to be very, very tight so that the data are used properly with an eye to, well, at least from public health perspective, um, when we decide to do analysis of data ourselves or else, um, that is only, because if we get answer 'a', we are going to take this course of action and we get answer 'b', we're going take a different course of action. In other words, it's got to be actionable insights, it's not just because it's nice to do that. You know, that's for other people to do analyses for, for those other reasons, but in government, it's really all about what do we need to use these data for and how will it change what we do. So it's really quite specifically tailored around translation.

COUNSEL ASSISTING

And again, being clear from the start about the purpose and scope and collecting as I think you put it the bare minimum rrequired to achieve

PROFESSOR D'ONISE

Yes.

COUNSEL ASSISTING

that purpose and scope.

In terms of those governance structures you touched upon earlier, both the ethics based one and, and the statutory based one have, have their own ways of governing data release and

data use. For a statutory system what are the key requirements or elements that need to be met when it comes to properly looking at data release?

PROFESSOR D'ONISE

So, it does depend obviously on how the legislation is designed, but if I can just take it from a general perspective, generally, um, legislation will have a component that can be used for service planning, obviously all de-identified, and the proper recipients of the data. Now that might even be those who reported the data to us. They may need to use that data for whatever proper purpose under the act. So there's that kind of, um, that kind of approach and the other, the other big arm is research. So a lot of these, well, the, the regulations that we work with have got provisions or the act that allows for research - it usually it says for medical or social purposes or something of that nature. Now when that's the case, then there are requirements that there should also be an ethics committee application for that project and from that, we also have to, there's also a governance part of an ethics. So there's a two part approval process. So, most of our data going outside would be for the purposes of research. And so they will all have to do ethics, um, governance approval. And then as a custodian, we look at, as I said before, what are the, what are the legislative rules? What has the ethics committee said? What have they been approved to use? We put that together and then we create the data set for them to use, de-identified.

COUNSEL ASSISTING

The robust nature of that process in your view, properly explaining that to hesitant members of the community, would that allay concerns if any particular, you know, parents might be listening and thinking, 'oh, how much more data on my children might be collected now' is, is part of this a public education process?

PROFESSOR D'ONISE

Yes, I think so. I think I, I will say that I'm not exactly, I couldn't give you a proportion of people who were worried and who are not worried. We, we are at the other end of the scale, but I have been involved in processes where the legislation's actually been going through parliament as well as the regulation. So I have seen the end to end, I do feel comforted that parliament is part of that, our elected members of parliament. So that gives me a sense that if it's getting through that process, our democratic process, then it's acceptable to the majority at least and yeah, I guess the really important part for me is reassuring people, but also talking to people about, you know, what is proper use, you know, what, what do you consider proper use as well? And, and I guess all of those systems that we have in place to protect the privacy and confidentiality of data, I mean, I think, absolutely professional agencies and professions within those agencies are absolutely critical. This is not an informal or rushed sort of process. It's very methodical, very clear. We have, you know, auditing processes within our own agency to check things. There are systems in place if something doesn't go perfectly, right. That happens actually at the national level, so that things can be remediated rapidly. I think, I think the maturity of the system is really critical. And I would also say that in that regard building a new system needs to borrow on that maturity. It can't really, it's not, it shouldn't, there should be no

novice legislative systems within the current legislative environment. I think that it requires maturity across the board

COUNSEL ASSISTING

Commissioner.

COMMISSIONER

Thank you, thank you so much. I wanted to dig in a bit. You probably would've heard us talking at earlier stages of the Commission about dynamic data. I think we can envisage the world, but the world we live in now, we get periodically the Australian Early Development Census and we get a whole population level, and then we can break it down to more localised levels and we have a lot of data about whether children are meeting developmental outcomes, whether more of them are behind in developmental outcomes, whether the way in which they're behind is changed over time or all of that sort of stuff. You can imagine a comparable system with child development checks, which would give you a greater data flow for the zero to five age range. But I, I think in addition to that, there is a more dynamic question about data around children and their immediate lived experience. So for example, if a child development check showed that a child was, you know, very much not meeting developmental milestones around speech, and there was a, you know, referral given to a speech pathologist, whether there would be data that would help that person referring assess whether or not the speech pathology service was ever accessed, and if it wasn't, what was the barrier, speech pathologist available, cost, to highlight, you know, could be a series of other barriers, transport, not facilitating appointments or with those sorts of things. Now obviously the privacy concerns in the second example are much, much more than in the first example. Can you, you know, talk, talk to us about, about that, about data systems around those kinds of more dynamic making a difference for an individual child and the considerations there?

PROFESSOR D'ONISE

Yes. I mean, I will say that from a privacy perspective, if an individual and a family are directly receiving a service and getting benefit from that service, I think that does mitigate some of the privacy concern because naturally if you're receiving a service in our world you know that that is being recorded somewhere. So I think there's a direct benefit to the individual. And I think that's a critical point of difference if you like, um, with those kind of bigger population based systems. I absolutely think, and it obviously depends, and again, on the purpose of the strategy that we are trying to meet, but absolutely data systems can do that. We, we had an example this morning about an, an equivalent, but slightly different, um, system from Department of Human Services. One of the benefits of that kind of system is that it allows us to look at quality and safety in a way in which we currently cannot. And by that, I mean you know, we talked about having a minimum standard of quality, so that, that would be part of it, but we also know, you know, where, for example, do we have service gaps, massive service gaps. It might be a regional area. It might be a community within south Australia who are just not reaching the service. Those systems would allow us to actually identify that. And then, you know, there could be a policy arm that reaches in there could be a service arm that reaches in

to fill that gap. So that, that would be absolutely critical But we can also look at, and I realise this, this is moving, um, perhaps into a, a bit more difficult territory, but we can look at performance, so we can look at the performance of, uh, the State, how we're doing as a State, how we are doing as a region of the State, how are we doing as a community and how, how, how even are we doing as a service. So that service can be at the service level, can be at the individual practitioner level. Now there are examples within the health system whereby, and this is, I won't say that that part has been an easy transition, but I will say that over it's, it is actually decades, of being used to working with data and using data that, that clinicians now, many of them will have benchmarking, so they will see their performance. They'll see how they match up against what is considered a standard, the best practise standard of care. We can also look at outliers. So for example, that might be the, you know, the doing really, really well, but we also can look at those who are not doing well, and then information can be fed back. Now that obviously is a sensitive matter, but if it's done well and competently it really can improve. It can lift the whole quality of the system. Yeah, I, I do think it's an, it is an important part because, you know, I guess we heard this morning as well about how professional development can lift the quality of early childhood. Well, these sorts of systems would be able to naturally evaluate an intervention such as that as well. So, in an ongoing way, will allow us to know how we are going, where do we need to intervene? Okay, we've intervened here. Now we need to check out how did we go with that intervention? And then in the years down the track, we can link to other systems to say, well, actually did that intervention lead to a difference in outcome. So that's where we moved beyond the process of what we are doing is in a service to an actual outcome. So I think as a learning system, as a, a safety and quality system, absolutely it, it would be useful, um, complex to put into place, of course.

COMMISSIONER

And in that health parallel where, you know, practitioners are basically getting feedback about how they're going against the range of outcomes that the practitioners are achieving, is that sort of system a legislative system, or is it designed and supported by the communities of practise? So, you know, the psychiatrists have decided, yes, this would help us foster quality and so we want to buy into doing it.

PROFESSOR D'ONISE

Yes, generally it's not legislated. I mean, I will say that medical practise is heavily regulated and so it's kind of hard to separate our duties in that way, but it's certainly voluntary and we find that more and more groups within the health system are standing up to the plate and wanting to take this path. So I do think it has been a cultural shift, a very positive one. Um, yeah, and, and legislation generally not, not required. There is another layer in the health system, root cause analysis. So that, that actually happens under protected legislation. And that's really to allow really in-depth assessment of what we think has gone wrong so that we can learn, and then that's a, that's a protected space, um, with our mortality committees. So I guess though, um, important to mention though, because it goes to the way of thinking of health that it's actually okay to look at what went wrong. In fact, you should look at what went wrong. You should learn from it. We should be putting things in place we should be improving. So this whole kind of continuous improvement cycle is absolutely supported by our data.

COMMISSIONER

And in that sense, the looking at what went wrong isn't, is not in a,

PROFESSOR D'ONISE

Not punitive

COMMISSIONER

Not in a punitive framework.

PROFESSOR D'ONISE

No, it's a learning framework. Yeah.

COMMISSIONER

And you were here for the evidence this morning where we were talking about how the system here in the State that we were discussing immediately before lunch was originally built by basically, I think Counsel Assisting's words were stock, take a stock take of what was already in the hands of government that wasn't being joined up. To build a data system for early childhood education and care is that you would imagine is the comparable starting point? You would stock take and see what you have, why you have it, whether those systems are communicating, if so, how could you get them to communicate? And for what purposes would that data then be made available?

PROFESSOR D'ONISE

Absolutely. And, you know, if the data already exists, we do have the Public Sector Data Sharing Act. So I guess that, that's part of that investigation phase. So do we already have legislation we need, are there any gaps? And, um, and I think being spectacularly clear about the strategy, like, you know, what do we want to achieve in the early years? And then that's the basis under which we do the mapping and see what exists and look at, you know, what, what could we do about standardisation and getting buy-in from all stakeholders? So yes, it would be a multi-stage process. The other thing that we would want to do is to look at, does such a, a system exist anywhere in the world and what can we learn from what's already gone before.

COMMISSIONER

Yep. And clearly, clearly in healthcare, there have been times when you've had to manage, for good public health purposes, data collection that people were very concerned about because of stigma. I'm thinking for example, of the early days of aids/HIV, would that be a good example of that? People would obviously worry that their child or their family could be the

subject of shame or stigma, based on sort of data collection in, associated with early childhood education and care. I mean, what, what are the lessons from health with dealing with that?

PROFESSOR D'ONISE

So I think, I mean, maybe, perhaps it is easy to go back to decades ago with HIV and aids, um, as opposed to contemporary examples. I think it's really important that the systems that are dealing with the data are also connecting very strongly with people with the lived experience so that we, um, that's that building of trust which is absolutely critical and, and also that mutual understanding. So I think that, um, and I, and the other part is that there needs to be value for those individuals. And certainly if a person already has HIV, the value's not going to be preventing infection, but it might actually be information going into treatment options. And so I think if people understand that, yeah, they have a value proposition for themselves or for their community. I think that's really important, yes. There's one other, um, oh, the other part is that, you know, if, if data are collected under a legislative framework, that that legislative framework has a very clear in a way ethical approach. So that can often be seen in the objects of the act where it's clear what it, what the reason for the collection is. And I think actually being completely tight about who can use data, who can make the decisions, is helpful in that regard. Very loose, open ones that allow, you know, data to be used in whatever manner people like, or, or even have political interference or what have you - that's where I think people get worried. But I think if we, if we've got really clear rules, we have agencies who are engaging with the communities, as well as collecting the data, using the data that data gets fed back to communities, and they have a value proposition. I think that that's how I would approach it.

COMMISSIONER

We heard evidence before lunch, and you've referred to it just then, of drawing on people with lived experience, and you've talked about how parliament ends up bringing, you know, a diversity of views to considering a legislative proposal around data. Have you seen good examples of involving those with lived experience in helping inform that legislative approach or co-design that legislative approach?

PROFESSOR D'ONISE

Yeah, perhaps I'll, I'll go to more general, rather than specific, but absolutely where we've had, really good engagement from the broad range of stakeholders, including people with a lived experience is where we have, I think the most useful and valuable kind of output of those. And I would suggest that that goes well beyond data systems. That's in our regular health promotion work as well. That, being clear that we don't have the only lens and getting all the different views, yeah, I look, I just, it's such a core pillar of public health practise. Now that it's hard for me to have, think of an example where we have, you know, separated actually the decision making from the people with a lived experience or just with the different perspective. It's it is a core practise and I, yeah, I, I've already talked about data as a pillar. That's another pillar of public health. Okay.

COMMISSIONER

Thank you. That's been very helpful.

COUNSEL ASSISTING

Thank you. The witness can be released.

And for the last witness today, I called Professor Andrew Whitehouse, last witness before this evening's session.

< PROFESSOR WHITEHOUSE AFFIRMED

COUNSEL ASSISTING

Professor, are you currently the Director of CliniKids at the Telethon Kids Institute?

PROFESSOR WHITEHOUSE

I am.

COUNSEL ASSISTING

We will come back to CliniKids in a moment, but are you also Professor of Autism Research at the University of Western Australia?

PROFESSOR WHITEHOUSE

Yes, I am.

COUNSEL ASSISTING

And I believe you're also the Research Strategy Director of the Cooperative Research Centre for Living with Autism.

PROFESSOR WHITEHOUSE

I am.

COUNSEL ASSISTING

Is it accurate to describe some of the work you do or the work done by CliniKids as a network of clinical centres for children with neurodevelopmental differences?

PROFESSOR WHITEHOUSE

That's right.

COUNSEL ASSISTING

Before we come back to that, have you published in over 300 peer review journals?

PROFESSOR WHITEHOUSE

Yeah.

COUNSEL ASSISTING

That sounds like an awful lot of work.

PROFESSOR WHITEHOUSE

I had lots of help.

COUNSEL ASSISTING

And I was fascinated to read that you currently present an internationally syndicated video series called 62nd Science.

PROFESSOR WHITEHOUSE

I do yes.

COUNSEL ASSISTING

And have written a book with your brother?

PROFESSOR WHITEHOUSE

I believe I have. Yes. Yeah. Keep it in the family

COUNSEL ASSISTING

Sounds like you are very busy.

Today we are going to focus on the work done by CliniKids. Can you tell us more about CliniKids and the work that it undertakes?

PROFESSOR WHITEHOUSE

Absolutely. Yeah. CliniKids is the community health arm of the Telethon Kids Institute. Telephone kids Institute is a medical research Institute in Western Australia and South Australia. We've got many different research aims, but we really do have a very strong focus on the community health aspects and in particular child development. A few years back the Institute, with my urging, was very keen to ensure that rather than simply being at the discovery arm of the research pathway, it was in the implementation of the pathway. One of the things in particular about child development, autism, certainly, but child development more broadly is that discovery research has happened for the last 30 or 40 years. And we have a host of things just waiting to be put into practise. And that's an important element of research. And so, through CliniKids, the Telethon Kids Institute sought to really be that change that we wanted to see. It was, it took the aim of that. It took the view that there is enormous amounts of research waiting to be implemented, but it needs a, almost an innovation factory that can, package it up, test the models so that busy overloaded systems can then export those models into their systems. Yeah.

COUNSEL ASSISTING

I was particularly interested in the written submission that you've provided to the Royal Commissioner, which is on our website, that there's a current estimate that research advances take a minimum of 20 years to be implemented into clinical practise. What's the source of, of that estimate?

PROFESSOR WHITEHOUSE

It's come from a scholarly paper. Yeah.

COUNSEL ASSISTING

Can you give us some practical examples as to how research activities are embedded within clinical activities in CliniKids, and we will come to a moment to Inklings, but just generally?

PROFESSOR WHITEHOUSE

Yeah, absolutely. One of the key things is that it has to be conscious and intentional. At the moment with regards to our both private and public systems, the caseloads are, are overwhelming and there are simply no space to, space, both physically, sort of time wise, and financially, to understand ways of doing things differently. And the ways that we are operating child development at the moment are based on models of 30, 40 years ago. Whereas the research literature is advanced. We are still stuck in our clinical models at the moment based on, um, 30 years ago, due to simply not having that space. And so what CliniKids does is that, is conscious and intentional about investment around individuals who have it as their sole remit to take ideas that are out there that are well and truly published, that have well and truly stood the sort of stress test, and then think about how they can be implemented into models that are not just acceptable to families, but are feasible to clinical service models. I'm talking

money, how can it make ends meet, as well as nurture workforce that remains engaged and wanting to work there. And then how does it actually be effective when you put it in on the ground? So it's intentional in terms of investment in people, investment in data collection and investment in buying out clinical time to ensure that we complete that feedback loop

COUNSEL ASSISTING

And the clinic it's got, I think more than 50 researchers and clinicians working side by side in this space.

PROFESSOR WHITEHOUSE

Yes we do. We've got about 60 people and, and again, it's really within broad based clinical services at the moment. There is no space to be able to do that kind of innovation work, to take existing knowledge, try and package it up in a clinical model that could potentially work anywhere, test it, because we need to test it within, within that to see - is it feasible; is it acceptable to people; does it make ends meet; is it effective - and then train as many people as possible? So that's really what the model is. Yeah.

COUNSEL ASSISTING

And can I now ask you to describe to us Inklings, which is a very clear illustration of this translation of good research into good practise without the 20 year timeframe.

PROFESSOR WHITEHOUSE

Absolutely. Yeah. That, that, 20 year timeframe, really, I got to a point about five years ago where I was, not just sort of knew that, from the scholarly literature, but also I knew that from my own practise. I'm lucky within the Institute to be within, be very exposed to a whole lot of other models, clinical and medical models. Kids with brain tumours in particular are a very interesting example that I've sought to learn from where, very fortunately we get few, but still we still get children who have brain cancer and because it's small numbers, every child often within each State are enrolled within clinical trials. And there's no way, no, no reason that we can't do that within this other area. And so, Inklings is a really good example of, of that as, as you mentioned. I've spent the last 20 years working with kids on the spectrum and our current clinical model, essentially the way of working with these kids is children develop differently very early in life. We can often see kids in the second six months, the first year of life and somebody notices something that's developing differently about this child, but because our systems are not geared up to accept referrals for these kids so young, we're still working on a 20 year, 30 years ago model, but we know that based on current literature, we can identify these kids. These kids bounce from health service to health service and disability service to disability service till they land on someone's desk at age 3, 4, 5, receive a diagnosis of autism. And then off they go for receiving therapies and support. Meanwhile, those first few years, amazing brain building years are, are left completely untouched, unsupported. And not just that, it's not just the idea of neuroplasticity, which is absolutely true, but it's the things that we put the families through, their concerns go unheeded. So the first interaction with services in a

clinical way is after two years of fighting and to get to get to that point of receiving support. So this was a, a model that based on currently we know is outdated. So we said, well, what happens if you do test that new model? What happens if we identify these little bubs showing early developmental differences very early in life and actually respond to those concerns. And so with colleagues, and I just, important to mention University of Manchester, Latrobe University, and also our colleagues at the Child Adolescent Health Service within Western Australia. So this is a private and public, research project. We first developed an intervention now called Inklings, and then applied that to children who were developing differently at six to 12 months of age. We've done a couple of clinical trials. The second one, just to touch on, these babies received this particular type of support, and happy to go into that in a bit, at an average age of 12 months, very, very young. And we then, about five or six months that the therapy period is, and then we followed them all the way up to age three and actually, compared to the control group who did receive a lot of intervention, that control group, these children who received Inklings, their level of disability was reduced to the point where actually, they were less likely to meet clinical criteria for autism. And the key aspects, what this, and as I said, this is a replicated clinical trial now ready for implementation, the key thing here is that it was prompt access to parent empowerment type support, and that had made all the difference.

COUNSEL ASSISTING

Before we work through some of the finer details of, of the nature of the trial, for people who might not have a proper understanding as to what autism is, can we just go back to basics?

PROFESSOR WHITEHOUSE

Absolutely. Autism's what we call a neurodevelopmental condition, which means that something happens early on in development to make the brain develop differently to what we typically expect. Autism is a most often, in fact, almost always, a genetic based condition. There are a whole lot of different genetic pathways that can cause the brain to develop differently, but we don't know enough about genetics and we don't know enough about how they influence brain developments. We diagnose what we can see, and that's the same as every neurodevelopmental and behavioural condition. And what we can see is behaviour and that's social communication differences and restricted and repetitive behaviours. Certainly over time, we've seen a really large increase in the numbers of kids who are receiving a diagnosis of autism, many different reasons for that. But the key issue is that there are many, many children who are struggling within the developmental pathways for them within our current system. And I think that our systems are almost entrenching a lot of that disability by how they're interacting with them.

COUNSEL ASSISTING

And did I hear or understand you correctly earlier that about three years is the earliest at which diagnosis are currently made in Australia?

PROFESSOR WHITEHOUSE

I think on average, I believe we, we are looking at about age four to five, but certainly with expert eyes, and with some children who have shown quite clear diagnostic behaviours often around, it's not uncommon for a diagnosis at age two years. Yeah.

COUNSEL ASSISTING

And was the one of the, the premises of Inklings then that there are some signs of development that can be gleaned and are visible earlier than that, that are then amenable to proactive intervention.

PROFESSOR WHITEHOUSE

Absolutely. And it's a very classic example of the research practise gap, the 17 to 20 years that we do see, perhaps for the last 10 or 20 years. There's been very clear ways that we are able to identify children very early in life who are developing a bit differently and with very good, what we call positive predictive validity, which is if you are showing these behavioural signs very early on, it's a high likelihood that you will receive a diagnosis later on. And so in Australia often the, the tool that we used within the clinical trial is something called SACS-R, which is quite a, very good tool in, in, in identifying these behaviours very early in life. And so yes, we can at six to 12 months of age, but currently our systems are not doing that.

COUNSEL ASSISTING

And if I understood you correctly, the science behind that in terms of being able to understand some behaviours much earlier than three, we've known about for a long time.

PROFESSOR WHITEHOUSE

Yes.

COUNSEL ASSISTING

But that evidence hadn't translated into any proactive interventions earlier than, than about that age.

PROFESSOR WHITEHOUSE

It's exactly right. And that was, it's a, again, going back to CliniKids, it's a really, it's a nice example of the *raison d'être* of that kind of innovation factory that can actually say, hang on, why are we doing it this way? There is another way, let's test it and export that model to everyone else.

COUNSEL ASSISTING

What did the model involve? Talk us through what a participating family received.

PROFESSOR WHITEHOUSE

In the inklings therapy? Absolutely. So, um, when we are looking, um, with babies, obviously everything needs to be directed through family. Kids don't exist in isolation, they can only exist, with adults who care for them. And so the way, what, what often happens when babies that young, who are showing early developmental differences, babies often come to us with parents feeling that their babies are not particularly fond of them, cause they're interacting, their babies are interacting with them in a different way.

COUNSEL ASSISTING

What might some of those differences be that you can identify at that early age?

PROFESSOR WHITEHOUSE

So babies may be, they may have different types of eye contact. And so parents may be seeking eye contact to, you know, engage and seek validation and they might not be there. Babies may have very focused attention on certain toys and it might be hard to shift that attention or from that toy to a more social, what, what we would typically see in the world is a more social orientation to humans. There might be less spontaneous social behaviours in terms of smile, social smiles, and all of the things that as parents, parents are, attuned to thinking is what is a typical type of development and interaction. Now that interaction cycle, sorry, those differences, which are sheeted back to genetic differences in how, how little babies are interacting means that that interaction cycle between parents and their babies or the caregivers and their babies is interrupted in some way. And actually that two way interaction, that back and forth serve return interaction, is the building block of all brain development. And if kids are not receiving the social enrichment and environment around them, quite simply their brains won't develop in a way that takes advantage of that, that social environment. So what the program does is use video based feedback. So videos are a really powerful tool to help parents understand who their little baby is, how important parents are to their baby. Number one, who that baby is, and how they're interacting, that they are interacting with them just in a different way and what they can do as parents to enrich that social environment around the child. Humans are born extremely undercooked and, there's no animal in the animal kingdom born as undercooked as us. It's not just important for children to get that social environment around them. They need it for their brains to develop. So through a 10 session, five month interventional program, parents are shown all of these techniques about how they can understand who their baby is, how they can identify when their baby is communicating with them and how they can then change the way they communicate to ensure their babies get that environment around them that they need to develop.

COUNSEL ASSISTING

What range of allied health specialists were undertaking the program with parents who were involved?

PROFESSOR WHITEHOUSE

The, in the trials we've done, speech pathologists and clinical psychologists have been the key professions that have been involved. It's really important to sort of say this is a really quite disability type model where we have a high threshold of entry. So each child must be shown quite frank differences and then referral off to a specialist. That's the model we use for the clinical trial. And it has a great, it has very good evidence behind it. Couple of clinical trials. I, I think there's also a great merit in thinking about adopting a population health model for these types of, interventions, which is where we use low threat threshold entry. So kids can gain prompt entry into it. And, I think that's some of the challenges where we see wait lists at the moment.

COUNSEL ASSISTING

And is that an area where you, you think you could even further reduce that, that idea of the 20 year gap in terms of, of designing and implementing an intervention that can be widely taught to people beyond an allied health circle?

PROFESSOR WHITEHOUSE

Yeah. Absolutely. I think that the, the extreme shortages that we see in allied health professionals, paediatricians, at the moment is unlikely to be solved, I don't think it's controversial to say, that it's unlikely to be solved simply by training more people. Every workforce sector at the moment has significant human shortages. And so something like an evidence based intervention like Inklings doesn't necessarily need to remain in the domain of allied health professionals. There are training courses that people can, that people go through. And then there's a certification process that people go through that can give broader professionals access to the skills here, and then, and then to be able to deliver it. And certainly across our early learning system provides a major opportunity for that as well.

COUNSEL ASSISTING

We will return and explore that concept of, of scaling or rolling out. But I just wanted to go back to some more of the practicalities around the, the clinical trials in terms of the participants that you've had undergo, so far. What was the retention rate like?

PROFESSOR WHITEHOUSE

The retention rate was very high and that that's very unusual for clinical trials in this area. Usually you see quite a high attrition rate. So we're talking sort of 60%, 70% retention. In this one in this clinical trial, we had upwards of 90% retention across three years within the clinical

trial and there's no doubt in my mind that a good part of that was because families could intuitively see benefit in these types of programs. These programs are about helping them as parents and caregivers understand who their little human is and how they can, how they can better communicate with that, that little human within their daily life to help them be who they want and need to be. And that kind of intuitive type program is so important to programs.

COUNSEL ASSISTING

As part of the accessibility of that program, was, were the video sessions undertaken at, at the child's home?

PROFESSOR WHITEHOUSE

They were, yes, they were and that's a really important element of it as well, because you, you are there within the family's everyday practice. So you can see the logistics of what home life is like. It also frees up clinical space. You know, having someone uproot their life, drive an hour to see you within a clinic and then drive back an hour, it, it is a really disconnected type of model. Um, and yeah, it also frees up clinical space as well.

COUNSEL ASSISTING

What sort of feedback were you given from the parents and carers who were involved in terms of the accessibility of the program?

PROFESSOR WHITEHOUSE

Yeah, for them, I think there's, I'll split that answer into two. One, broadly, in terms of the immediate, um, the, the feedback was overwhelmingly positive and, and the retention rate really bears that out as well. The view was that every child should have access to this. Yes, I understand my child's developing differently, but every parent should have access to this so they can know who their little human is because it helps them become better parents. During the hurly burley of child rearing, that's a really important aspect in terms of the children who went on to still receive a diagnosis of autism. They were well on their journey before meeting the disability world. They were, they understood who their little child was. They understood that that child needs to be nurtured and celebrated for who they are, rather than necessarily altered or changed. And that's a really important reframing that's important to that family, and that child, and that they are engaging with the disability system from the very first get go, empowered and ready to navigate. And that's a, just much changed from where we're at now.

COUNSEL ASSISTING

And you touched earlier upon the inherited nature of, of autism. Can you explain for us in simple terms, how the intervention can make a difference for some, albeit acknowledging that some will go on to still have a diagnosis, made?

PROFESSOR WHITEHOUSE

Yeah. So one of the key findings from the clinical trial was that it actually reduced disability to the point that many kids didn't make criteria for autism or a significantly lower proportion of kids didn't make criteria for autism. At age three, when I started training, that was science fiction, we were taught that kids were born with fundamental genetic differences, which meant that from birth, these kids were destined to develop clinical autism. What we understand is that children are born neuro divergent in the sense that they interact and process the world in different ways, but that parents can make, caregivers can make, a fundamental difference in the developmental trajectories of their children. What this program, what the clinical trials have shown is that through that interactive pattern, by actually providing parents with the knowledge and skills that was always within them, but the program helped bring it out to give that social environment around them, children had reduced social communication difficulties. So they were better able to communicate socially and in communicative functions in daily life and also reduced restricted and repetitive behaviours. So kids, once we're seeing lower behaviours on these, they're less likely to meet criteria for autism. Now they remain neuro divergent, but their disability within the world is fundamentally reduced. And that is just a fabulous thing for everyone.

COUNSEL ASSISTING

And for those children who didn't go on to have a formal diagnosis made, how, how stable would you expect that to be? Is there a moving trajectory from, from say three onwards where you might see changes if the child isn't followed up?

PROFESSOR WHITEHOUSE

Yeah. Great, great question. It's important to say that we followed these children up 18 months after the end of the program, which is a really good, decent period to show those kind of, um, the lasting persistence of those types of effects. The final time that we have seen them, we, we are planning, to see them again, it was at age three. Currently, what we do know is that in terms of an autism diagnosis, we have around 90% stability for a good diagnosis from a high quality diagnosis at age three, all the way through to age 10. And so we would expect about 10% of kids to switch diagnostic categories at age 10 but still is quite a, quite a high stability from a diagnosis at age three to age 10.

COUNSEL ASSISTING

And from a, a caregiver or parent's perspective, the, nature of advice given to them in the early stages I imagine can't be underestimated, no matter what eventual diagnosis is made, in your view?

PROFESSOR WHITEHOUSE

Yeah. And this is, this is the crux of population health, is that we need to deliver programs and messages that is, is that are beneficial for everyone. Absolutely at nine to 12 months of age,

there are tools like the SACS-R are that able to tell us with a high degree of, you know, a certain degree of confidence that these kids are on a different developmental path, but nothing is a hundred percent proof. So we need programs that are not just not harmful for everyone, but beneficial for everyone as well. And so this is what this Inklings program is as well.

COUNSEL ASSISTING

And having undertaken the two randomised control trials to scrutinise this program, what, if any work is Telethon Kids doing at the moment to consider broadening out access to Inklings?

PROFESSOR WHITEHOUSE

Absolutely. The National Disability Insurance Agency has been very interested in these findings and how it can apply to the broader NDIS across Australia. And I think, so we are in advanced negotiations and discussions with them around what that looks like. Certainly, I have great, I think there is great promise in a, in a collaboration in that regard. The key things here is, is in terms of the discussions, is the interface between State based services and federally based, or, you know, the NDIS is a, obviously a cost sharing arrangement predominantly administered by the Commonwealth. The NDIS has a major role in supporting kids through an insurance based model and insurance based model in terms of providing early support to hopefully prevent later disability and associated costs. At the moment, the interface between early childhood and the NDIS is breaking down to a point where there is cost shifting going on between State and federal and the NDIS. So models that we're talking with the NDIS is around how we can leverage off State based screening services and the NDIS base funding for therapy type services. And I think that model, with a very clear division of duties has enormous promise to benefit both systems. Yeah.

COUNSEL ASSISTING

In terms of the qualification level of people delivering the Inklings program, you mentioned before the range of allied health specialists that were involved in terms of the trials and you indicated there's scope within the nature of your program design to allow it to be taught to people perhaps without those qualifications. How long does it take to train someone in the intervention?

PROFESSOR WHITEHOUSE

Yeah. Takes around three, three to four months to train people on this intervention. The cost is around \$2,500 to \$3,000 per person and that provides not just training, but a certification process to ensure quality standards. And for an implementation, for example, across South Australia, you're looking at about 18 to 24 months, and around 10 clinicians, when in full flight. The key thing about Inklings is that, I really want to present this point with a, a strong degree of humility - there is nothing rocket science about Inklings. What it has done is packaged up everything that we know from 30 to 40 years of research, about how we can support kids and parents who are struggling. And that's what it's done. It's put it up into, into a package, put it into 10 sessions, very clear structure. And we went through the hard yards of testing it, it so

happens that it is really effective in supporting kids. So in terms of how we provide support to kids, we absolutely must back evidence. It is, we do it in every other area of health and medicine, and it is so crucial that we do it here. We can't let ourselves off the hook with that.

COUNSEL ASSISTING

In terms of that, I keep coming back to this 20 year gap, but it, it's quite mind boggling to, to be colloquial. How do you envisage a program like Inklings staying on top of research and then continuing to embed it so that the, the program stays up to date without risking running behind?

PROFESSOR WHITEHOUSE

Yeah, there are two challenges there. One is how do you implement at scale? And then how do you not let it run away from itself? There are, sort of the, the way that I've conceptualised this over the last two years is sort of a, a stepped kind of process. And, and it's really, I've learnt, a lot of it's influenced by my experience with the NDIS and many other systems around how we can leverage the good, while learning from, from the challenging aspects. So, number one, I think that in early childhood, just like we do with every other area of health and medicine, is we must back evidence. And that means picking. We must pick evidence based program. We have an aversion to that in the area of early childhood whereas in, the previous speaker talked about cancer, we absolutely back evidence.

COUNSEL ASSISTING

Do you have theory as to why there is an aversion in the early years space?

PROFESSOR WHITEHOUSE

Yeah, I, I think, I think having been in the space for many, many years, I think that many of the techniques that we use are, are very common to many different types of approaches, but that doesn't mean that every approach is created equal. We have to hold ourselves to the high, the standards that every other area holds itself to. And that means going through the clinical trial process and then backing those that have done that. And to say that finding evidence in this area, because it means working with humans rather than cells or whatever, it is hard, we just simply can't accept that as a reason. So, number one, it's picking discrete programs with evidence, and identifying those key ingredients of those programs. There's a lot of stuff within programs. What are the key evidence ingredients, just like the active ingredients of any medication, then it's really around creating the strong structures, almost the soil in which this, this program that can be planted, that nurtures quality, accessibility, affordability, and accountability. And I can go into each of them. Quality is absolutely non-negotiable. Quality slips very easily in this area, again, because it involves humans working one on one with a, with an individual. Quality can slip really easily. It can also be really easily made high. Accessibility. We can't have programs that restrict accessibility because often, particularly in this area where we're seeking to get to families who are often the hardest to, to access, and they find us the hardest to access too. Affordability. It needs to be as cheap, if not free, as

possible. That's our guarantee as a society to kids and families, we need to give them a guarantee that they have that safety net. And accountability. That goes back to the quality or the quality thing we were talking about before is that, is that if we are, if we are to hold ourselves to the same standard that each, each other field of health and medicine holds themselves to, we have to have accountability, which means quality indicators, and, and hold people to that. In terms of all of those, that does need a private and a public function I believe. The private function is simply because there is no system within Australia at the moment that has demonstrated the capacity to accommodate all demand. And it's going backwards. And there are many reasons for that, obviously but again, we need to follow the evidence. There hasn't been a public system that can account for all of the demand and then, but then must be a public system to provide that safeguard mechanism for everyone in our society. And then finally, we must incentivise those things. One of the challenges that I've observed in other systems, certainly the NDIS would be one, is that it incentivises quantity over quality, and we must incentivise quality in this field. That, that can mean remuneration type incentives. It can mean career type incentives, but there are many other incentives that can be used with very smart economists around that know how to do this, but we must incentivise the correct things, not just pushing kids through. But it's about quality as well, and then continue to innovate. And that is, that's where that accountability comes back in, is that you must collect data to ensure that it keeps the program honest on all occasions.

COUNSEL ASSISTING

And in your view, does that also then assist in trying to avoid this lag that we've seen?

PROFESSOR WHITEHOUSE

Yes, it does. Yes, it does. And it, and it keeps public trust in a program. When you collect data it ensures that this is not about people pushing barrows or one campus vs. another. It's collecting data because this is the health and wellbeing of our kids. This is the horse we're backing at the moment, when a new horse comes, that'll be backed, but at the moment, here's the data. How can we continue to improve then?

COUNSEL ASSISTING

Anecdotally, the parents and caregivers who've been through the Inklings program, what can you tell us about attitudes towards data collection and what were they told and, and what were the varying attitudes towards it in this space?

PROFESSOR WHITEHOUSE

I think, the first thing to say is families took part in this program because, look, they would've received some, some support, but they know that the support they would've received would be relatively limited. And so they were so grateful of somebody listening to concerns at, at that point in life. In terms of the collection of data, this was a research project. So people are well, sorry, this has been a research program. And we have very strong links with the community, within, across Australia and within our local community as well and so families are participating

knowing that this is about data collection. At the same time in this particular area, when your child's developing differently, I would hear more often than not how, how much families want to give to the next generation; 'that if my experience here can help other kids and families have a better experience then we will absolutely do it'.

COUNSEL ASSISTING

And before I hand over to the Commissioner, you used a lovely phrase when I spoke to you last week about taking a program like Inklings, and I hope I'm quoting you correctly, out of disability and into the population. How might you see that occurring within an early childhood education and care context, say for example, given the opportunity South Australia faces?

PROFESSOR WHITEHOUSE

So the disability type model is, is what I was talking about before, which is basically almost a, a 'wait to fail' type model where we wait, wait, wait, and, oh, yes, you are showing a certain level of disability so we'll refer you off to a specialist. What we've seen through other systems, and again, the NDIS would be an, an interesting system to look at here, is that's driven huge demand that supply simply can't keep up with in terms of clinicians. And so we have wait lists really going out beyond what is reasonable. And so that key aspect of prompt access, this is key. Absolutely all the techniques within Inklings are well evidenced and over 20, you know, 30, 40 years and the clinical trials show it out. But one of the key aspects is prompt access. It's the time in which these kids are coming in. And so that disability type model high threshold off to a specialist, which often has a wait list means that we do miss those early, very early years, really, in more occasions than not. In terms of how we can translate that into a different model, the population health model, which means that low friction entry, you know, even if parents might want to receive the program, that might be enough and that means that they can receive it promptly within their local community. And that requires broader individuals who are able to deliver it. I think the early learning system is a really, is a really major opportunity in which again, this program, which we know has great clinical evidence can actually be learnt and delivered by educators within that setting. And it is a unique opportunity that I believe that South Australia has here to think about how do we get kids and families prompt access, because the clinical model in and of itself of referral off to a specialist is not going to give any of us that prompt access and the lowest friction entry into a program like this that I could see would be within the early learning system.

COUNSEL ASSISTING

I think you underestimate the program by saying it's not rocket science, but my last question is, would you characterise some of its strengths as being the fact that you've been able to strip decades of research into a program that is capable of being rolled out relatively, simplistically is not the right word, but easily rolled out if the right infrastructure is there?

PROFESSOR WHITEHOUSE

Absolutely that that's exactly it. We're standing on the shoulders of everyone who's gone before us and have just stripped out all of the key findings and put it within a 10 session program, done the clinical trials and they found, found to be efficacious. The key functions that we're at now is how is this implemented so kids can get it faithfully, you know, with fidelity, with high quality, promptly and in their local communities. I think that one of the original sins of early childhood in Australia is that we built it around health touchpoints rather than around community touchpoints. And I think a program like this has a really important function in connecting families back to their communities so they can have it delivered within their local type communities and early learning systems is one aspect of that.

COMMISSIONER

Thank you. I want to ask you some questions about Inklings, but also more broadly on ClinKids and research translation. So I'm just going to push you a little bit on, if you were designing the early childhood education care system so that it could buttress, support and assist with the rollout of Inklings what would you do? I mean, clearly, these are more associated with, if you're talking about zero to 12 months, which from your evidence, you know, 12 months seems like an important age, you do have some children in childcare settings in that age range, but it's not the peak period for being in childcare, that comes when children are a little bit older. But children are intersecting with, you know, community nurses, with children's checks and the like. Are you thinking that there would be some inquiry in that sort of children's nurse, potentially playgroup environment, around the sorts of questions, which would lead someone to then say to a family you might want to think about X or Y? I mean, obviously you've been dealing with families who have developed a set of concerns around their child, but there may well be some families who haven't got a clear vision of what, you know, usual development is like for a 12 month old. So they're not even noticing that their 12 month old is not reacting the way we would say are sort of average reactions.

PROFESSOR WHITEHOUSE

Yeah, absolutely. So the Inklings program is for kids six to 18 months, and so it does actually extend towards more high, high, intense, or sorry, more frequently used, childcare ages. I think one thing that is absolutely crucial here is that it is around building in house expertise in, in these types of programs. I think that at the moment a referral function, so somebody at playgroup or childcare has noticed something different, they may say something or may prompt a referral off to a specialist, that has a really important function for kids showing really significant developmental differences, and clinical attention is absolutely warranted in those instances. However, with every referral touchpoint, we lose a certain proportion of kids and families, they will just simply not follow up that referral function and they will sometimes remove themselves from that community. So building in-house expertise for people to receive these types of programs within their local community without a referral is absolutely critical in the implementation of it. And so in-house, in-house expertise such as say an Inklings lead educator, who can, not just maybe attend to the kids with the more high developmental

vulnerabilities, but also supervise, provide, professional development to that early learning centre inhouse, I think is really, really crucial as well.

COMMISSIONER

So that would be strengthening the skillset around recognising that a child may be neurodiverse in some way and the sorts of things that you convey to parents about how to interact with the child, you know, to, to keep building strengths. The early childhood educators and childcare workers would have a line of sight around that and the ability to deploy it.

PROFESSOR WHITEHOUSE

That's right. Yeah. Not just a line of sight and absolute ability to deploy that. So we don't lose kids through referrals. If kids are spending six to eight hours a day within an early learning centre, it is an immeasurable opportunity to change the quality of their development across their, and, and impact their life later on. And so within that actual development, within that actual early learning centre is the opportunity I'm talking about, delivered by early childhood educators.

COMMISSIONER

Right. Understood. And, and you would also, I think you referred to, that South Australia could, I think it was, in 18 to 24 months by building a network of clinicians could also lift the clinical interface.

PROFESSOR WHITEHOUSE

Absolutely. So that was talking about the clinical model. If, if we were simply looking at a disability type model, which is upskilling allied health clinicians, certainly one way of implementing this.

COMMISSIONER

In the perfect world, you have both.

PROFESOR WHITEHOUSE

You would have to have both.

COMMISSIONER

Because you wouldn't get a referral of every child and, and even if a child was referred, the carer working with that child for what might be six to eight hours a day or whatever, it's important for them to have the skills in any event.

PROFESSOR WHITEHOUSE

One hundred percent. And so, you know, with population health, we talk about broad based measures that everyone gets, as well as still a referral function for kids with high developmental needs. In my submission, I provide a really interesting example that happened in the UK around mental health. I'm happy to talk about that. The IAPP model, essentially the UK provided a, got to the point, like every system around the world, where mental health referrals were just piling up and GPs were the ones who were dealing with it. GPs don't necessarily have the advanced skills and so people were not necessarily having the care and wait lists were piling up. They come up with a two-tiered model where essentially they had a high intensity and a low intensity workforce. High intensity workforce was for specialists who received people with moderate to severe depression and anxiety and they received the referrals. So those specialists were still receiving the referrals they would've beforehand, but they also trained a new workforce, not traditionally involved in mental healthcare, community workers, social workers, others, and they trained them on an evidence based program, cognitive behavioural therapy. They picked a winner. So I was talking about, they picked evidence, we're going to do this. And they, this new workforce, the low intensity workforce receive referrals for children, sorry for adults who yeah, low, low to moderate severity. And it's proven to be incredibly successful because the key thing was prompt access to evidence. And that's the one thing that we're lacking or two things that we're lacking at the moment.

COMMISSIONER

Yeah. That's the Beyond Blue new access model is a comparable access model.

PROFESSOR WHITEHOUSE

Absolutely.

COMMISSIONER

Moving from Inklings to what you do at CliniKids more broadly. One, one thing that strikes me from some of the discussions we've had at the Royal Commission is, you know, we know a lot more than we used to about childhood development, particularly brain development. But I still think you know, in terms of the biology probably we've uncovered the tip of the iceberg and, and, you know, research over coming years, it's going to uncover a lot, lot more for us. You would think that the degree of evidence about what is going on and what makes a difference will be coming pretty thick and fast. So we, we not only have the historic kind of challenge that you've pointed to, that there is a very big journey between the research efficacy being improved and it being deployed in a population health measure, that's making a difference for the maximum number of people. So that's your sort of 20 year journey now you know. Given you would think that new insights are going to be coming ever more quickly. What do we need to do, you know, systems wise to try and keep up with that? I mean, you know, we've obviously got CliniKids, that's thinking about this translation, but infrastructure wise in Australia, in other states broader than Western Australia, you know, what do you think that's going to take? Otherwise I fear that, you know, the research, and there will always be a cohort of people

because they've got financial and other sorts of resources will be able to access the best of the best of care and insights about their child, but we won't be deploying all of that new knowledge systematically for every child, particularly children at the most risk.

PROFESSOR WHITEHOUSE

So it must be conscious and intentional, I think would be my first point, is that innovation and, and an adherence to evidence-based practise never happens without a constant focus on it. And so there needs to be space, resources, and a culture that nurtures that. Without that, any other measure simply just will not even start. I think that we also need to get to the point where the soil is right for new innovations. And, just to use that gardening analogy, I don't think at the moment in any way our soil is right. We still have 'wait and see, wait and see, wait and see' when children are developing differently, when every bit of evidence, not just the neuroscience, but the clinical evidence shows that actually identify and act is absolutely the way that we reduce later disadvantage and disability. And so we need to first get the soil ready for that. And once the soil is right for that, we're all of a sudden on an even playing field. So I would, I guess it's a twofold answer. Number one, we need to get ourselves up to current best evidence. Then number two, we need to develop, there, there needs to be within every system, a mechanism that has a space where innovations can be tested, adopted, sorry, tested, the tyres kicked on it and adopted if found to be beneficial. It won't happen without a conscious and intentional mechanism through which that can actually occur.

COMMISSIONER

And just to draw you out a bit on the, the wait and see, so you think that's partly cultural, I guess, but it would partly be a perception about cost control driven wouldn't it

PROFESSOR WHITEHOSUE

Yes, most definitely.

COMMISSIONER

Don't medicalise until you need to medicalise.

PROFESSOR WHITEHOUSE

Yeah, absolutely. And, probably not that latter one, I would say that it's more the former in the sense that the use of a diagnosis at age three, four or five was a, you know, once upon a time, a really great indicator of developmental disability. And, and so waiting to that, it really said, well, all of a sudden, we've got a really clear indicator as to where resources could and should go. One of the things about the NDIS is it has actually given tangibility to the dollars that are spent and are saved by investment in the early years. Whereas before, when we talk about investment early in the early years, they are hypothetical figures, we're talking about dollars saved. Whereas, something like Inklings, the dollar savings are manyfold, based on NDIS type figures. And so the false economy of 'let's wait and provide resources only to those that have a

diagnosis of autism', for example, has been shown to be incorrect. Now that the NDIS, now that we've done health economic modelling around the Inklings program, which has been supported by the great data collection within the NDIS.

COMMISSIONER

Yeah. And I mean, one, there's the, there's the research clinical trials, giving you the evidence, taking it out into the community, more generally testing it in the community more generally. But then there's the public policy interface, isn't there, you to upscale Inklings, for example, you need to persuade state governments and potentially the federal government to invest in this model. You need to persuade a whole lot of people who work with children to get themselves across the model and to think about what role they could play in identifying children who need support or supporting those children. I mean, can you, can you think of changes that might mean that journey of translation that you are on now with Inklings could be quicker and more efficient than the journey you are on? I mean, I appreciate you're mid journey. You've done it all in West Australia. You're now talking nationally, presumably that's got its moments of joy and its moments of huge frustration, but, reflecting on that experience, can you think of what would've made all of that easier?

PROFESSOR WHITEHOUSE

Yeah. I think in terms of early childhood, there are significant challenges at the moment in terms of the interface between state governments and the behemoth of the NDIS. The NDIS is extraordinary. It's changed many family's lives. I see it every day. It's also come to be seen as a bit of a wicket keeper for children who are developing differently. And it has meant that the interface between state and federal services has been a little bit more challenging and, you know, these are all tangible issues. These can be solved, these types of issues. So I think in terms of public policy, I think a clearer delineation as to responsibilities in that space, I think would be really helpful for kids and for families and in terms of how we can react to evidence, and innovation. If when we, when you think about other areas of health and medicine, there are very clear pathways to having a medicine that is all of a sudden now part of the standard, you know, medication use within a particular condition. We don't have that within early childhood and even more, we don't have a register of anything that is delivered. Now I'm not saying to go down the huge bureaucratic pathway of register and regulation, but there absolutely needs to be a recalibration back to quantity, sorry, quality. And so why is this one program that sticks out beyond others? There needs to be, you know, the evidence is manifold, manifest, but we do need is a very clear way to be able to make distinct those with very clear evidence must be invested in because it's good for our kids vs. those who don't have the evidence. And so I think there is both the system issue between state and federal that we do need to continue to solve and it's, and it's getting better but I think that we also need to understand and be very clear about what levels of evidence that we will be then seeking to implement with our kids.

COMMISSIONER

Thank you. It's been very helpful. Thank you. Fascinating work. Thank you so much for speaking to us.

PROFESSOR WHITE HOUSE

My pleasure.

COUNSEL ASSISTING

Commissioner, we will reconvene at six, but for the general public, that will be uploaded tomorrow and we will adjourn then formally until our April settings.

COMMISSIONER

I believe you're generously giving the general public the evening off.

Thank you everybody for your support for today's hearings. Thank you for everybody who's done all of the technical things in the back. We will convene online for this evening session. Thank you.

< HEARING ADJOURNED UNTIL 6.00PM