



TRANSCRIPT OF PROCEEDINGS

THE HON RONALD SACKVILLE AO QC, Chair
THE HON ROSLYN ATKINSON AO, Commissioner
PROF RHONDA GALBALLY AC, Commissioner
MS BARBARA BENNETT PSM, Commissioner

**THE ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND
EXPLOITATION OF PEOPLE WITH DISABILITY**

SYDNEY

9.59 AM, THURSDAY, 27 FEBRUARY 2020

Continued from 26.2.20

DAY 8

**MS K. EASTMAN SC appears with MS S. FRASER and MS G. WRIGHT as Counsel
Assisting MS K. MORGAN SC appears with MS A. MUNRO for the Commonwealth of
Australia**

MS G. FURNESS SC appears with MR I. FRASER for the State of New South Wales

COMMISSIONER SACKVILLE: Good morning, everybody. And good morning also to those who are following the proceedings remotely. This morning, as on other mornings, we commence by acknowledging and paying our respects to the traditional custodians of the land on which we are meeting today, the Wann-gal people. And we
5 also pay our respects to First Nations elders, past, present and emerging, as well as to any First Nations People who are present today. Ms Eastman.

MS EASTMAN: Good morning, Commissioners. Good morning to everybody in the room and those following on the webcast. I understand yesterday there might have been some patchy disruptions in the webcast. So if there were, I apologise and
10 also hope that things will be a bit easier today.

Commissioners, today we turn to the evidence from a number of the government witnesses. We will hear first from New South Wales Health and then later in the day from the Commonwealth and then the NDIS Commissioner.

Can I make this observation about the evidence that you'll hear from the government
15 witnesses. We have not asked those giving evidence on behalf of the government today to respond to each and every one of the direct experience witnesses that you've heard over the course of almost two weeks. So where you've heard evidence about people's particular personal experience with health services and the like, those are not matters that we have asked the government witnesses to address specifically.

20 But we have asked them – and you recall I said this in my opening for week 2 on Monday – that we have asked the government witnesses to reflect on some of the themes and issues that have emerged over the course of the past week or so. And so I may ask them questions that address their reflections on what their learnings have been over the past week. I will assume, but I will check, with each witness that he or
25 she has followed the proceedings or had the opportunity to read the transcript.

So there are also going to be a very large number of matters that over the course of the life of this Royal Commission that we will need to investigate and may be the subject of public hearing on the area of health, and also its interaction with a number of other areas. Some of those may be the way in which guardianship decisions are
30 made. Some, which has emerged from the course of the evidence over the past two weeks, is the interaction with disability services. And it's likely to raise issues in relation to interaction with employment, interaction with housing, interaction with education.

35 So I cannot, in the course of the time available today, cover a very wide range of issues that concern the government witnesses, both for New South Wales and for the Commonwealth. And even in the area of health, the government witnesses have provided very comprehensive and detailed statements. What the Royal Commission hasn't seen, but those, perhaps, having a glimpse of the folders behind you, is that there's a vast amount of documentary material that has been provided to the Royal
40 Commission.

So what I wanted to do today, in dealing with each of the witnesses who are speaking on behalf of the various governments, is to touch upon key themes and key issues. And I would hate anyone following the Royal Commission proceedings to think that we're seeking to overlook or skip any issues. It may be that we will come back to these issues. And I think it is fair to say for any of the governments, either participating in this proceeding or other State and Territory Governments that the Royal Commission has a lot of work to do in the future and it is very likely that all of the witnesses may have to return at some point in time. And it's very likely that this Royal Commission will seek to follow up some of its lessons learnt from hearings such as this hearing and some of our other hearings and return to some of these topics to see whether there has been any progress in the life of this Royal Commission.

So, by way of introduction, can I just preface the way in which you'll hear the evidence today, is that we've tried to take quite a selective approach so that we identify particular issues, but we don't intend today to try to cover everything. So, having said that, can I ask Dr Lyons now to come to give his evidence.

COMMISSIONER SACKVILLE: Yes. Dr Lyons, if you would be good enough to come forward. And please take the oath or affirmation, as you wish.

20 <NIGEL LYONS, SWORN

[10.04 am]

<EXAMINATION BY MS EASTMAN

COMMISSIONER SACKVILLE: Thank you. Please sit down, Dr Lyons, and Ms Eastman will ask you some questions.

MS EASTMAN: Good morning, Dr Lyons.

DR LYONS: Good morning.

MS EASTMAN: So you are the deputy secretary, health system strategy and planning for the New South Wales Ministry of Health?

30 DR LYONS: That's correct.

MS EASTMAN: And you've prepared two statements for this hearing of the Royal Commission.

DR LYONS: I did.

MS EASTMAN: They're both dated 13 February.

DR LYONS: That's correct.

MS EASTMAN: And have you got a copy of both statements with you?

DR LYONS: I do, thank you.

MS EASTMAN: All right. So let's deal with the first statement. That sets out your
5 relevant professional background. And it also deals with a range of policies. And
this statement, the first statement, answers a number of questions asked of you by the
Royal Commission, which you've identified in paragraph 5. So that's just to identify
the first statement. And you've read the statement?

DR LYONS: I have.

10 MS EASTMAN: Are there any corrections or amendments to the statement?

DR LYONS: No, there are not.

MS EASTMAN: And the contents are true and correct to the best of your
knowledge and belief?

DR LYONS: They are.

15 MS EASTMAN: Commissioners, you'll find a copy of this statement in tender
bundle part C behind tab 2. And I'll deal with the tender of this document now. So I
tender that. And it will be marked as exhibit 4.27.

COMMISSIONER SACKVILLE: Yes. Thank you.

20 **EXHIBIT #4.27 FIRST STATEMENT OF DR NIGEL LYONS DATED
13/02/2020 (STAT.0066.0001.0001)**

MS EASTMAN: Dr Lyons, you've provided a second statement, also of 13
February. You've got a copy there?

DR LYONS: I do.

MS EASTMAN: And this statement is directed to answering the questions as you
25 describe in paragraph 2. So that's questions 5, 6, 7 and 8(a), together with some
additional questions; is that right?

DR LYONS: That's correct.

MS EASTMAN: That just helps me identify that we've both got the same
document. And are there any amendments or corrections to this document?

30 DR LYONS: No, there are not.

MS EASTMAN: And are its contents true and correct to the best of your knowledge and belief?

DR LYONS: They are.

5 MS EASTMAN: And, Royal Commissioners, you will find a copy of this statement in part C of the tender bundle behind tab 3. And if I can tender this statement, and it will become exhibit 4.28.

COMMISSIONER SACKVILLE: Yes.

10 **EXHIBIT #4.28 SECOND STATEMENT OF DR NIGEL LYONS DATED 13/02/2020 (STAT.0067.0001.0001)**

MS EASTMAN: So, Dr Lyons, you were here, as I've just explained the purpose of the evidence. I hope that gives you some comfort that I'm not going to ask you each and every aspect of health policy in New South Wales. But our focus will be on
15 some of the matters identified in your statement. Can I ask you, first, have you followed the Royal Commission proceedings over the almost two weeks?

DR LYONS: So I've been provided with daily updates from the team who have been present. Unfortunately, I haven't had the time to be as closely involved in following all of the proceedings, but I have been able to get updates from the team
20 who have been here.

MS EASTMAN: Have you been provided the transcript of the proceedings to date?

DR LYONS: No, I have not.

MS EASTMAN: And the daily updates comprise what?

DR LYONS: A summary of the issues as they've related to health, in particular the
25 New South Wales Health system, if anything has been raised.

MS EASTMAN: And they've been prepared by the lawyers representing New South Wales Health; is that right?

DR LYONS: They have, and the team who are here from the Ministry, as well.

MS EASTMAN: So I want to start by asking you some questions about the overall
30 structure of the New South Wales public health system and to then look at each layer as we go through as to the various responsibilities. But can I start with a general question. In reading all of the material, are we right in understanding that there is no one person or no one specific designated role in New South Wales Health that has

specific and exclusive responsibility for the health of people with cognitive disability?

5 DR LYONS: In terms of specific responsibility and designated, there are many people who have responsibility, but if you're looking for a one focal point, then in our – in our governance and management of the New South Wales Health system, the Secretary of the New South Wales health system has a range of responsibilities, including overarching responsibility for all aspects of the systems as a system manager. So we have very clear responsibilities under our governance arrangements, and in relation to the services that are delivered. But, ultimately, the Secretary of
10 New South Wales Health would be the ultimate person responsible.

MS EASTMAN: Right. But the – that would be the person responsible, but in terms of then underneath the Secretary, as I understand it, there's designated roles and positions that have particular areas of responsibility across the Ministry for Health; is that right?

15 DR LYONS: That's correct.

MS EASTMAN: And in that layer, there's no one specific person or designated role with just specific and exclusive responsibility for people with cognitive disability?

DR LYONS: Not specific and exclusive, but that is incorporated into the role of a range of people, including myself, as one of the deputy secretaries. So, within the
20 division I have responsibility for, I have teams who have responsibility, so Health and Social Policy team, the Inter-government Relations team have components of what they do with designated individuals who support a range of functions to support not only people with cognitive disability, with other disabilities. So it's in the functions of the components of the Ministry and there are resources that have
25 responsibilities in relation to a number of those functions.

MS EASTMAN: All right. And we will get to some of those resources and functions, I think, in a moment. So you've provided a very comprehensive overview in your statement about the structure of New South Wales Health by reference to the legislation. And so I want to ask you about the role of the local area district. So if
30 we look to your statement, this is paragraph 11. So this is the first statement. That there is an overall Health Department, but if we're looking for where do we find, I think as one of the witnesses described, the coalface. The coalface starts by looking at the 15 Local Health Districts; is that right?

DR LYONS: The service delivery components of the health system, yes.

35 MS EASTMAN: So you might have to help me with some of the technical language. When you say "service delivery", what do you mean by that?

DR LYONS: So that's where all of the clinical services, the hospitals, the community health services, the mental health services are provided from from that component of the system.

5 MS EASTMAN: And so the organisation of the Local Health Districts means that these are organised on a geographical basis?

DR LYONS: The Local Health Districts are. And then there are Specialty Health Networks, as well, that have State-wide responsibilities. So the Local Health Districts, yes, they have responsibility for a certain geography and a certain population.

10 MS EASTMAN: So if we wanted to understand the delivery of health care services for people with cognitive disability, is our primary point, our starting point, at the Local Health Districts?

DR LYONS: In terms of how care's delivered in relation to individuals, patients, carers and families and what they receive from the clinical services, yes.

15 MS EASTMAN: And each of the – can I call them LDH, if everybody can follow.

DR LYONS: LHDs.

MS EASTMAN: LHD. It's getting late in the week. So maybe I'll just do Local Health District. So with the Local Health Districts, each of the districts is set up with its own board and its own director; is that right?

20 DR LYONS: That's correct.

MS EASTMAN: And each of the districts are ultimately responsible into the Ministry of Health and to the secretary; is that right?

DR LYONS: That's correct.

25 MS EASTMAN: And in terms of the organisation of each of the Local Health Districts, there is an obligation that each district conduct its operations consistently with the overall policies and directions coming from the Ministry; is that right?

DR LYONS: That's correct.

30 MS EASTMAN: So it's not a case that each particular district can develop its own particular policies in a particular subject matter area and just do its own thing autonomously.

DR LYONS: That's correct. Could I just qualify that, though. The policies frame and require the districts to comply with the content. How that's translated into practice will then be something the districts look at. And they will often look at

those and then translate those into components that actually, when you look at a policy that is written for a whole system, it's got to be contextualised to the local services. So they often make a translation about how that goes into practice at the local level.

5 MS EASTMAN: So is it the case that the policies are developed at a central level through the Ministry, the districts have to comply with the policy, but the translation of the policy from the words on the page to how it will operate in practice is the responsibility at a district level; is that right?

DR LYONS: That's correct.

10 MS EASTMAN: And do the district levels also have responsibility for monitoring, evaluating the implementation of policy?

DR LYONS: They may look at how they respond to the policies and have their own processes about how they assess that. In addition to that, from time to time, the Ministry will look at the system response and assess and review policies. So they're actually – they're not established and then set in stone. There is actually a review period. So there's usually a review undertaken in a reasonable amount of time after they're implemented to assess whether they're actually delivering as they've intended to and whether there's any improvements, requirements or whether there's any legislation or change that requires them to be updated.

20 MS EASTMAN: So would the review be undertaken with input at the district level, but then the review is undertaken at a central level; is that right?

DR LYONS: That's usually the process, yes.

MS EASTMAN: And is it the case that what might come from a review of the policy is reflection on how effective a policy has been in practice and whether it needs to be reviewed or altered or, in fact, replaced, depending on whether the policy's achieving particular objectives?

DR LYONS: That would be a component of the assessment, yes.

MS EASTMAN: And how does the Ministry ensure that the Local Health Districts understand the relevant policies and then implement the policies? Do you have, for example, a system of key performance indicators that each Local Health District has to meet?

DR LYONS: We have a range of mechanisms to ensure that, not just the policies, but a whole range of things that the system is required to deliver on are actively – how we deploy our resources, what activity levels are expected of the services, what performance is required of those services. As you can understand and appreciate, health is a very large and complex delivery agency and provides services – millions

of services each year to the community. So we've got many ways of actually assessing those.

We have service agreements that we strike with our Local Health Districts each year which have some components of those, but not everything. And we have reporting mechanisms around a whole range of things that are on a regular basis, including
5 quarterly meetings – at least quarterly meetings with the Local Health Districts and the performance management team in the Ministry to assess the performance and delivery. And if there are issues that are being highlighted, then they can be taken up in those processes.

10 But, in addition to that, we have ad hoc reporting requirements, as well. There are a whole range of other things that we require our districts to report on from time to time. If there are issues that are raised and we need to understand how things are being delivered or if there are – there is a need to ascertain whether something has actually been delivered as was intended, we can ask for those ad hoc reports.

15 MS EASTMAN: All right. So I think both you and I are going to have to slow down a little bit for our interpreters. So I apologise for the interpreters for speeding up today. But, also, I think, some of the expression and the terminology that we're using, if we can just slow down.

DR LYONS: Sure. Will do.

20 MS EASTMAN: Bear with me. All right. In terms of the service agreements, you've provided references to the service agreements for all of the Local Health Districts in your statement. And we've reviewed all of that material. It seems that there is a standard clause in the service agreement that requires the Local Health District to ensure New South Wales policies are understood and complied with and
25 services are delivered consistently with those policies. So I've paraphrased a particular clause of the service agreement. But is that consistent with your understanding?

DR LYONS: It is.

30 MS EASTMAN: Is there a sanction for a Local Health District that fails to meet this obligation to ensure that the policies are understood and complied with and services provided consistently with the policies?

DR LYONS: There are ranges of ways that the districts are held to account. And there's a performance monitoring regime with escalation within that regime around levels of concern. If not just policies aren't complied with, but services aren't
35 delivered or budgets aren't on track, there's a whole range of ways that that can be escalated through a performance management regime from the Ministry to the districts. But those are assessed with a whole range of inputs into them, not usually just one.

MS EASTMAN: Is there an audit function in terms of looking at compliance?

DR LYONS: So we don't have a regular audit function from the Ministry around particular policies, but if there was a concern that a policy was not being delivered effectively or if issues were raised that required, we could audit. But there are a whole range of ways that we actually assess whether the things that are happening in the districts are being delivered as we would expect. And there are complaints mechanisms, there's the performance monitoring regime that I spoke about. There are also issues around adverse events. When adverse events occur, they're investigated, they're reported centrally. So there are a whole range of mechanisms around how the Ministry is responsible for monitoring the services and the performance and the delivery of care at in our services.

MS EASTMAN: So what happens if in the course of the process that you've just outlined that the delivery of services are wanting or not meeting your expectations at a Ministry level for compliance with policies? What happens?

DR LYONS: It wouldn't just be policies, usually. There will be a range of factors looked at in relation to the concerns with a district. But if those were substantive issues, then in the performance regime the district may have its performance level raised, which then requires closer monitoring around what's happening within the district. Now, if there were particular issues around a policy raised through either complaints or adverse incidents, the Ministry could actually assess that they've got a problem in some part of the system. And if there's a policy that it relates to, then there may be an assessment of whether or not that policy is being complied with in the way it's delivered. Now, whether that's done at a district level or at a system level would depend on how much we're seeing a pattern of activity behaviour complaints, concerns, incidents, whether or not that's widespread or it's localised.

MS EASTMAN: I appreciate, obviously, there's so many different competing considerations in health, but the purpose of this hearing is to examine access to health and health delivery for people with cognitive disability. And in the updates that you've received during the course of the past week or so, no doubt you've been told that there's been many incidents that have been identified as raising concern about access. And there's some particular themes emerging. How can people with intellectual disability and then, also more broadly, cognitive disability know or understand the process that you've just described for reviewing and monitoring compliance with policies and other accountabilities? How can ordinary people know how people with cognitive disability are picked up in that process that you've described?

DR LYONS: We provide information to the community generally about the processes we follow. And we're as open and transparent as we can possibly be. But there are a range of mechanisms right from a hospital level or a clinical department level, through to the district, through to the Ministry, where not only do we publish our policies, our practices, but we report on performance. Independently of the New

South Wales Health system, we've also established the Bureau of Health Information that provides information to the general community about aspects of what we do.

And that's an independent board-governed organisation that will decide on various components of the health system that they would like to report on the performance of, will do an analysis of that part and then provide a report to the population, to the general community, and to Parliament. So there are a range of ways where not just as the system report what it's doing, but there's also then assessment about how the system is performing or delivering, which are open and transparent.

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MS EASTMAN: And for – so that, I assume, covers the whole of Health. But coming back to my question for people with a particular interest in understanding that process from the perspective of people with intellectual disability or that broader cognitive disability, I assume in your updates someone has told you how the Royal Commission is using the expression “cognitive disability”, and then intellectual disability being that subset. So coming back to just that particular area, how can we look at the process that you've described and find out information that's specific or relevant to people with intellectual disability or the broader cohort of people with cognitive disability?

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DR LYONS: I think that is an issue. And we've highlighted the need for greater ability to – to analyse data and highlight that in some of the statements, as well, about how we identify appropriately people with cognitive disability or intellectual disability within the context of the other services that we provide. And the need for greater ability to ensure that when a person is receiving care that we can actually assess for that individual the components that need to be in place.

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Now, we don't track people that way at the moment. We look at what services are delivered. But what has been highlighted and certainly has come out of some of the changes that have occurred with the move of people into the NDIA, the National Disability Insurance Scheme, I should say, is the fact that often we don't know whether they're actually a client of the National Disability Insurance Scheme when they come into our services even. So there is a - - -

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MS EASTMAN: That's so – that is a topic that I specifically want to get to.

DR LYONS: Yes.

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MS EASTMAN: But can I just bring you back just to this question. Am I right in understanding that at present time, if you wanted to look at the processes that you've described and pinpoint intellectual disability or, broadly, cognitive disability, you're not going to be able to find that in the current process?

DR LYONS: It's difficult in the current datasets. We'd have to use specific processes and do those prospectively to be able to assess those.

MS EASTMAN: All right. So no doubt in the updates you've been told about some of the statistics that have been shared with the Royal Commission about life expectancy for people with intellectual disability, about hospital admissions and that type of information. Has that come to your attention?

5 DR LYONS: It has.

MS EASTMAN: And in terms of what you're aware of in relation to that research, is there anything within New South Wales Health and your collection of data or review of policy or the monitoring process that you've described that would allow New South Wales Health to match its own records with what is coming out of the independent research over a period of time? Is that something that's been done?

10 DR LYONS: Not to my knowledge, and not specifically. But, having said that, there are a range of things that we're actually doing which recognise our acknowledgement of that research and the importance of actually responding at the service delivery level. And my statements cover a number of those things, which I'm happy to expand on for you.

15 MS EASTMAN: I want to now turn to some of the policies. So at paragraph - - -

COMMISSIONER SACKVILLE: Sorry. Just before we do that. As far as innovation is concerned, what room is there for the Local Health Districts to innovate. If, for example, it was thought desirable to introduce a scheme of advocacy for people with cognitive disability in a particular Local Health District, could that district do that without getting the approval of the Minister?

20 DR LYONS: It certainly could. And, in fact, we have many examples of where districts do test and try and evaluate local initiatives, and if they're demonstrated to improve how care is delivered. We've actually established at the system level whole agency with that responsibility. So the Agency for Clinical Innovation. I used to head that Agency for five years. It has the remit to actually learn from what's being done, tested and tried at a local level, and through its networks – and we actually have a network that's a responsibility for intellectual disability.

25 There's a designated network that is actually resourced to support not only testing and trying and scaling those initiatives, but also looking at what's available in the literature, understanding from experts, both within the services and across the state, about what we could do to improve care. And it actually has established a whole range of things which are included in some of the documentation that we have, which happy to provide to the Royal Commission, about initiatives that they've undertaken to improve care and provide those supports across the system.

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35 COMMISSIONER SACKVILLE: You refer to a network. Where is that network located?

DR LYONS: So it's based within the Agency for Clinical Innovation. So there are over 30 networks that exist. And they're supported by a network manager. And what they provide is a place for not just clinicians but carers and people who have an interest in the particular area to come together and be supported to look at what they believe needs to be done to improve care and to test, try and innovate those changes and provide supports for the system as a whole. And they've got amazing resources that they've actually provided for the New South Wales Health system, which we could provide to the Royal Commission, of given supports for our clinicians about the things they could do differently and better.

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10 COMMISSIONER SACKVILLE: And they've suggested, have they, experimental, if you like, programs, pilot programs for people with cognitive disability who enter into the health system so they could be assisted more effectively.

DR LYONS: Absolutely. Provided tools, resources - - -

COMMISSIONER SACKVILLE: Can you give some examples

15 DR LYONS:

COMMISSIONER SACKVILLE: Are you coming to that?

DR LYONS: Certainly.

MS EASTMAN: I'm happy to deal with this now.

COMMISSIONER SACKVILLE: Perhaps you could give some examples of the sort of innovations that have been suggested and presumably evaluated.

20 DR LYONS: Certainly. So if you will just bear with me while I - - -

COMMISSIONER SACKVILLE: Certainly.

DR LYONS: - - - move through some supporting documentation that I have. So the summary of - there are a whole series of things that the intellectual disability network - the resources and tool kits that they've provided as support. They've done research survey analysis. They've looked at research and development subcommittee discussion paper, so looking at guidelines for research in this space. They've looked at the Went West Child Development Care Coordination Project, evaluation applicability more broadly. And they've provided a position statement on the importance of an intellectual datasets. They've looked at policies that we've got in place and whether or not they can be provided resources around checklists to enable them to be implemented more effectively, which comes to the point I think that was being raised about how - - -

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30 COMMISSIONER SACKVILLE: Would you mind just slowing down.

DR LYONS: Sorry. I will speak more slowly. So this translation of policy into practice, how that can be supported through resources and toolkits like the checklists.

COMMISSIONER SACKVILLE: Are these published documents?

5 DR LYONS: They are. So they've also got in the education space some examples of storytelling around how we can improve care. So an example of improving the experience of hospitalisation for people with intellectual disability. It's actually a story about what's being done to improve and demonstrate. A disability awareness online training resource, which is available through our health education training institute. Videos that have been produced that are available on the ACI website.
10 There is one about intellectual disability and hospitalisation. There's another about intellectual disability and mental health. There's another about intellectual disability and respiratory health. So they're examples of resources that are available. They've produced reports for - - -

15 COMMISSIONER SACKVILLE: I think I might let – we might let Ms Eastman pursue this if it needs to be developed further. Thank you for that - - -

DR LYONS: Primary care, as well.

COMMISSIONER SACKVILLE: - - - reasonably comprehensive list.

DR LYONS: It goes on.

COMMISSIONER SACKVILLE: I'm sure it does.

20 MS EASTMAN: All right. Can I, perhaps, look at the policy framework.

DR LYONS: Certainly.

MS EASTMAN: And this is paragraph 42 of your first statement. And you say there that:

25 *Policy in New South Wales Health is developed and managed according to principles set out in the New South Wales Health Policy Directives and other policy documents.*

And if we were to understand what is a New South Wales Health policy, we might find them in a range of documents described either as Policy Directives, guidelines, information bulletins, policy and procedure manuals; is that right?

30 DR LYONS: That's correct.

MS EASTMAN: And in paragraph 43 you say:

The requirements for compliance with policy documents is as follows.

And over the page, so just dealing with each of these, there's a requirement to comply with policy directives. So is that a particular class of policy document?

DR LYONS: It is.

5 MS EASTMAN: And what is a policy directive that might be different from a guideline or a bulletin?

DR LYONS: It's about the level of adherence that's required. So, as you see in the statement, as it points out, that a guideline would represent best practice in a certain area. And unless there is strong reason not to, it should be applied. And then, in relation to information bulletins, it's about information that the – the district should
10 note. But it's about the level of compliance that's required. So the policy directive is the highest level of – and that's where there's a requirement that it must be complied with.

MS EASTMAN: Right. And then there's a sort of cascading approach to compliance.

15 DR LYONS: That's correct.

MS EASTMAN: Down to just noting or adhering; is that right?

DR LYONS: That's correct.

MS EASTMAN: Okay. Now, at paragraph 44 you set out what you describe as State-wide policies which have particular relevance to people with disability. I
20 assume, when you use the expression "disability" in paragraph 44 that you're talking about all form of disability?

DR LYONS: That's correct.

MS EASTMAN: And you haven't limited the list of these policies to people with cognitive disability; is that right?

25 DR LYONS: We haven't, no. They're broader.

MS EASTMAN: Right. We've reviewed all the policies that are referred to in paragraph 44, which goes over the page to subparagraph (dd). So that's pages 10 and 11. And I want to ask you about a number of policies which seem to us to be ones that are particularly relevant to people with cognitive disability and the subset of
30 intellectual disability. The first is in paragraph 44(f). And it's described as "guidelines on research, inclusive for people with intellectual disability". And then they're available on a website. So we've had a look at that document. And the guideline is expressed in fairly short terms and then there's a range of other accompanying documents. And this appears to be a document created by the New

South Wales Agency for Clinical Innovation. Are you familiar with this document - - -

DR LYONS: Not familiar with it.

MS EASTMAN: - - - or policy?

5 DR LYONS: It would be useful if it were available for me to review.

MS EASTMAN: I – as I understand it, with this document that you haven't included a hardcopy of the document, but just provided to the Royal Commission the website reference. But it's not something that you've reviewed in the course of preparing for - - -

10 DR LYONS: Not in detail. There's been an extensive range of information, as you'd appreciate. So it would be useful to familiarise myself with that particular - - -

MS EASTMAN: Perhaps I can just deal with it at a high level. If it is a guideline, would that fit into the area of it being adhered to to represent best practice?

DR LYONS: That would be my interpretation, yes.

15 MS EASTMAN: And with respect to guidelines in relation to research within the New South Wales Ministry, what is the relevance of a guideline about the manner and form of research? How does that fit into overall compliance, overall monitoring?

20 DR LYONS: It would be – I would need to familiarise myself with the document to be able to give you an accurate response to that question.

MS EASTMAN: All right. I'll see if arrangements can be made for a copy of that document, if it's not otherwise in the tender bundle. But we might skip over that. All right. I wanted to also ask you, before I went into that, with the list of the policies that you've outlined in paragraph 44, are we right in assuming that what
25 you've sought to do is to put them in alphabetical order, but not in order of importance in relation to the area of intellectual disability?

DR LYONS: There's certainly no categorisation around a hierarchy.

MS EASTMAN: I think we – and I'm not being flippant, but we rather assumed that putting animal visits and interventions in public and private hospital services
30 first was not intended to indicate that that was the primary policy?

DR LYONS: Well, it's clearly in alphabetical order when you look at the – when you look at the statement, so I think, to be fair, it's alphabetical order.

MS EASTMAN: That's our assumption. And so, because there's nothing in paragraph 44 that indicates which are the primary policies of importance for people with cognitive disability, this is why I want to go through our assessment of what we think are the important policies. Because it's fair to say, isn't it, that all of these policies might cut across a range of different areas, and the extent to which they're not only limited to people with disability of all kinds, they might be applicable to the general population, as well; is that right?

5

DR LYONS: Absolutely.

MS EASTMAN: So let me then ask you then about paragraph 44(m). And this is the New South Wales Health and Ageing Disability and Home Care joint guideline. So this is a guideline. Do you know if that policy is current and still operational in New South Wales?

10

DR LYONS: It wouldn't be operational, because ADHC no longer exist. So with the establishment of NDIS and our transition to the National Disability Insurance Scheme, ADHC as it was previously functioning is not operating.

15

MS EASTMAN: Why have you included that policy in the list of policies that are applicable to people with disability?

DR LYONS: Because it hadn't been rescinded. So those were still current at the time that this was put together.

20

MS EASTMAN: So this was still current at 13 February?

DR LYONS: It may not have been in active use, but it was still current within our list of policies, guidelines and the like.

MS EASTMAN: Well, what use is this if it's no longer operative in New South Wales to include it in the list of current policies?

25

DR LYONS: Well, it's still a policy. It is not in active use, though. It's not required, but it's still there and – within the list of policies that have been provided and are available.

MS EASTMAN: Looking at the list from 44(a) through to 44(dd), are there any other policies that you've included in this list that are no longer active?

30

DR LYONS: Well, not to my knowledge, no. But I'd have to go through – I mean, as you – as you know, it's a very extensive list.

MS EASTMAN: I know it is. We've looked at all of the policies.

DR LYONS: I'd need to go through and review those all individually.

- COMMISSIONER SACKVILLE: Can we assume that this list has been compiled by somebody else for inclusion in your statement?
- DR LYONS: There was a team within the Ministry that helped put this together. Yes.
- 5 COMMISSIONER SACKVILLE: Yes.
- MS EASTMAN: Can I ask you about the policy identified in 44(v) called Responding to the Needs of People With Disability During Hospitalisation. Is that a policy that you're familiar with?
- DR LYONS: Yes.
- 10 MS EASTMAN: All right. And if you need a copy of this, I think we do have a copy.
- DR LYONS: That would be helpful.
- MS EASTMAN: All right. And I'll just make sure that you're provided with a copy.
- 15 COMMISSIONER SACKVILLE: Ms Eastman, do we have a copy available - - -
- MS EASTMAN: I don't – I assumed that we did have all of these. We don't have them. Okay. We'll leave that. We don't have that one. All right. We don't have that one. So I don't want to ask you questions if you need a hardcopy of the policy. All right.
- 20 DR LYONS: Thank you.
- COMMISSIONER SACKVILLE: Well, perhaps someone could arrange to get copies - - -
- MS EASTMAN: I will come back to it.
- COMMISSIONER SACKVILLE: - - - then come back to it.
- 25 MS EASTMAN: All right. Can I ask you, then, about the New South Wales Health and Inclusion Action Plan. So this is identified in 44(n). And this is available. Would you like a copy of that?
- DR LYONS: Yes, please.
- COMMISSIONER SACKVILLE: If we don't have a copy, that's fine. You can
- 30 continue with Dr Lyons and we will – I'm told we do have a copy.

MS EASTMAN: This was a document that was included in Mr Simpson's evidence. And it is in part of tender bundle D.

COMMISSIONER SACKVILLE: Thank you.

5 MS EASTMAN: So I just need someone to turn it up. Commissioners, I'm sorry about this. The systems have broken down a little bit just in terms of having hard copies. I don't want to put Dr Lyons in any difficulty. So I might just leave the policies and I will come back to that. Can I make it clear - - -

COMMISSIONER GALBALLY: Can I ask a question before you - - -

MS EASTMAN: But can I just finish this?

10 COMMISSIONER GALBALLY: Yes. Sure.

MS EASTMAN: Can I make it clear, these are the policies I am going to ask Dr Lyons about. So this is to make sure we've got copies. Is I was going to ask him about the guidelines in subparagraph (f), about the Health and Disability Inclusion Action Plan in subparagraph (n), about paragraph (v), Responding to the Needs of
15 People with Disability During Hospitalisation; (x) the Service Framework to Improve the Health of People with Intellectual Disability. So those seem to be to us the key policies that I wanted to ask. Commissioners, if you have another policy in this list that you would like us to explore, let me know and copies will be made available.

20 COMMISSIONER GALBALLY: Well, mine's really a question about intersectionality. And some of these – it's not – it's just that when I look at the sexual safety. Sexual safety, you know, all the women's ones, I'm just wondering whether intellectual disability, you know, whether that intersectionality has been really highlighted and what your plans would be for the future in making sure that
25 disability is, you know, a really major part of general policies.

DR LYONS: And I think this is a work in progress because I think we would recognise that, as we revise policies, we look at whether or not there needs to be further information around the intersections and components that need to be expanded on. And certainly that has been the case with a number of them that have
30 been reviewed, but – but not all would have as much detail as we might like to around particular aspects of certain groups within our services that need particular care. And that's often where we – when we have feedback about system issues or reports or complaints or investigations that have occurred, that, as we do the update, we might highlight certain aspects and reframe those.

35 COMMISSIONER ATKINSON: Well, shouldn't all your guidelines and policies deal with these issues for people with cognitive disabilities?

DR LYONS: Well, they – they do, in part, and the extent to which they cover them in detail, whether that detail is adequate, is what’s reviewed as to whether or not there needs to be greater detail provided.

5 COMMISSIONER ATKINSON: Are you effectively saying that, at present, they don’t effectively cover these – they don’t all effectively cover that?

DR LYONS: Well, we provided the policies that we thought were appropriate and relevant because they did intersect.

COMMISSIONER ATKINSON: Sure, but what’s the answer to my question?

10 DR LYONS: There’s no doubt that we could do better in – in some of the areas, and – and what we are doing is continually revising and – and improving as we update those policy directives.

COMMISSIONER ATKINSON: So is that a long way of saying yes.

DR LYONS: That we could do better?

COMMISSIONER ATKINSON: Yes.

15 DR LYONS: Yes.

COMMISSIONER ATKINSON: Thank you.

MS EASTMAN: All right. Commissioners, I may leave the policy issues. I’ve identified the policies, and you will probably see a little bit of a flurry of activity so that everybody has got a hard copy of them. They could probably also come up on
20 the screen but I think, to assist Dr Lyons, it would be helpful him to have a hardcopy.

COMMISSIONER ATKINSON: Yes. We’ve got electronic copies of them.

MS EASTMAN: But I am going to leave that for the time being. And someone will let me know when that’s organised and assembled, and away we go. All right. Can I jump a little bit to a different topic and we will come back to policies. And I want to
25 ask you about some matters that you’ve dealt with in paragraph 94 of your statement. So this is page 22. So you tell the Royal Commission that the mental health branch of the Ministry was invited and provided two staff members to attend a Roundtable that was held in Sydney in March 2018. And the result of that Roundtable was a document called A Joint Communiqué. You see that?

30 DR LYONS: I do.

MS EASTMAN: Were you personally involved in this?

DR LYONS: I wasn’t, no.

MS EASTMAN: All right. But you're aware of it?

DR LYONS: I am.

MS EASTMAN: And the Royal Commission heard some evidence last week, when Professor Trollor came to the Royal Commission last Thursday about the joint
5 communiqué, and he was asked some questions about the proposed timeframes and –
and initiatives set out in the communiqué. Has that been brought to your attention?

DR LYONS: It has.

MS EASTMAN: And in your statement you say that New South Wales broadly
10 supported 24 recommendations, and as at this – February this year, has fully or
partially implemented 16 of the recommendations, and you note that responsibility
for implementing the remaining eight recommendations resides with the
Commonwealth. And you refer in paragraph 97 to:

A copy of the response to recommendations.

So have you got a copy of that document?

15 DR LYONS: Not in front of me. No.

MS EASTMAN: Do you – in preparing your statement, did you look at the 24
recommendations and identify what recommendations have been accepted and what
hadn't?

DR LYONS: I think it's about the interpretation of the "fully and partially
20 implemented". So I think – yes, I have seen the recommendations and I have seen
our response to those.

MS EASTMAN: Right.

DR LYONS: What I would say is that, for many of those recommendations, we've
25 made a start on implementing. To say that they're fully implemented and in a
sustained way for the system would be an incorrect interpretation, but there has
certainly been action at the system level in relation to those.

MS EASTMAN: All right. So I do have a copy of the – this document, which I will
provide to you, and there's also copies for the Royal Commission. And do any other
parties need a copy?

30 DR LYONS: Thank you.

MS EASTMAN: So is this document a document that you've seen before?

DR LYONS: It is.

MS EASTMAN: All right. And were you involved in the preparation of this document, or somebody has prepared this for you; is that right?

DR LYONS: It's been prepared for me.

5 MS EASTMAN: All right. I just want to understand when you have given some evidence just a moment ago about the way in which the recommendations are broadly supported or have been fully or partially implemented. Are you able, looking at this document, to identify which of the 16 recommendations have been fully implemented? And I'm asking you this because I wasn't sure, looking at the document, where we could see that there has been full implementation. And so I just
10 need your assistance in relation to that.

DR LYONS: So I would say that there are – there aren't any that I would say would be fully implemented. They would either be partially implemented. I'm not sure that there's any we could say would be completely implemented. There has been substantial progress on many of them.

15 MS EASTMAN: But why did you say, in paragraph 96, that:

The recommendations, as at February this year, have been fully or partially implemented.

DR LYONS: So, you know, to take the example of 4.3, access to multi-disciplinary teams, we've – we're substantially progressed in implementing those teams to be
20 available within the system. So it depends on the interpretation of whether you would say the recommendation is implemented or not. I mean, we've actually got a process to establish those teams. They're well advanced. They will be operating within the next month. You know, it's about how close they are to – to full or – but – but to be fair, I think it would be generous to say that they're fully implemented.

25 MS EASTMAN: Well - - -

DR LYONS: I think they're more partially than fully.

MS EASTMAN: So would it be better to look at your paragraph 96 and retract the reference to “fully implemented” and just maintain them as “partially implemented”?

30 DR LYONS: I think, on reflection and review of the detail, that would probably be a more appropriate response.

MS EASTMAN: So with respect to the partially implemented recommendations, when we looked at the communiqué last week and some of the timeframes, the communiqué indicated that some of the recommendations should be implemented during the course of 2019. You're aware of that?

DR LYONS: I'm not aware of the detail of what things were in the communiqué around what time frames.

MS EASTMAN: Right. And accepting that the communiqué is not New South Wales policy, and accepting that the communiqué doesn't bind New South Wales Health in any way, as we understand it, that acceptance of the recommendations from the Joint Communiqué was entirely voluntary; is that right?

DR LYONS: My understanding that, at this stage this is – was a Roundtable convened nationally. There's further consultation to occur with the jurisdictions, which will occur in the next month or two. At that stage, this – there's the whole concept of translating what was discussed in the Roundtable and to a National Roadmap, and to have recommendations with indicative timeframes after that process. So there hasn't been a lot of discussion with the jurisdictions, I think, at this stage, other than having a couple of representatives at the – at the Roundtable, who wouldn't have been speaking with any authority around committing the jurisdiction.

MS EASTMAN: I'm about – I'm about to ask you about the National Roadmap.

DR LYONS: Okay.

MS EASTMAN: But I'm just coming back to this piece of work done in March 2018 and the timeframes set out at that – on that occasion. And just understanding, now, in relation to partially implemented 16 recommendations and accepting, as I said, that this is entirely voluntary. This is not an initiative of New South Wales Health. And you've undertaken to commit to the recommendations, as I understand it, not as committed policy; is that right?

DR LYONS: Correct.

MS EASTMAN: But to the extent that New South Wales broadly supports the 24 recommendations, can we take it that New South Wales has found those recommendations to either be consistent with existing New South Wales policy, or, alternatively, recommendations that can enhance and improve existing New South Wales policy; is that right?

DR LYONS: Yes.

MS EASTMAN: And to the extent that the recommendations have been supported by New South Wales, the purpose is to take those recommendations and implement them within the existing structure and policy framework in New South Wales; is that right?

DR LYONS: That's correct.

MS EASTMAN: And so with respect to the partial implementation, are there any particular priority areas of the 16 or so recommendations that are set out in this

document that the New South Wales Ministry has identified as being matters of importance? Or is it the case that, given the Commonwealth's initiative, that you're now waiting to see what might come from the Commonwealth before further advancing these initiatives?

5 DR LYONS: We're well advanced on many of them. So when I said "partially" rather than "full implementation" I shouldn't underestimate the advances that we've made in many of these areas over the last 18 months, two years. And I will give you the example of the Intellectual Disability Specialist Teams that we've established. We had – I had three.

10 MS EASTMAN: I want to ask you about that.

DR LYONS: Well, I think it's important to highlight, because I think this is reflecting the relative starting positions of New South Wales as comparison with many other States and Territories. And the National Roadmap is looking at – looking at an overarching national approach. I would say to you our relative starting position is actually very good by comparison, and we've got many of the elements already in place. So in responding to the evidence and my statement about the partial and full implementation, many of these are well advanced.

15 MS EASTMAN: But this communiqué is only focused on quite a narrow issue, mental health needs of people with disability.

20 DR LYONS: Correct.

MS EASTMAN: So not just across the board on all aspects of health.

DR LYONS: That's correct.

MS EASTMAN: But I just – I will ask you these questions because I wanted to understand exactly what you meant in paragraph 96 in terms of the nature of the support and the extent of implementation.

25 DR LYONS: Mmm.

MS EASTMAN: All right. So this continues to be a work in progress.

DR LYONS: Absolutely.

MS EASTMAN: Can I ask you, in relation to the timeframes for implementation, that we seem to, I think, can assume, can we not, that we've slipped for some of them, in terms of the timeframes identified in the communiqué. But are we right in understanding that, notwithstanding that slippage in time, they remain matters where New South Wales is committed to the implementation?

DR LYONS: So – so the – so I think they’re two separate things and I think we need to see them as separate things. I mean, this was a Roundtable that was established nationally and a communiqué that came out of that meeting. In addition – and separately to that, we’ve got a whole lot of work that we’re doing within the context of our policies, our directions, in New South Wales, many of which are well advanced by comparison. And, as I said, the Intellectual Disability Mental Health Hubs, as one of the examples, those Teams are well-established and almost up and operating. I suspect if you looked at the communiqué or we looked at the roadmap that might end up being produced, that may be not a short-term, given the level of investment that’s required and the ability to get those Teams up and established, but we’re – we’re well advanced in New South Wales in that.

MS EASTMAN: Okay. All right. I want to ask you about that in a moment. While we’re dealing with the National Roadmap, you’ve addressed this in your statement paragraph 91. So you’ve noted – and this is the first statement – that:

15 *In August last year, the Commonwealth Minister convened a Roundtable.*

And you say:

New South Wales Health was not invited to be involved in any roundtables thus far.

But we understand New South Wales Health will be participating in an upcoming Roundtable; is that right?

DR LYONS: That’s what my statement says.

MS EASTMAN: All right.

DR LYONS: Yes, in formal communication, that we will have a Roundtable that we’re invited to in April 2020.

25 MS EASTMAN: Has - - -

COMMISSIONER SACKVILLE: But there were two representatives at the 2018 Roundtable from - - -

DR LYONS: So – so they may have been people who worked in the mental health space, but may not have been there representing the jurisdiction. So they – I – it depends on which capacity they’ve been invited, I think.

30 COMMISSIONER SACKVILLE: What capacity could they be invited to attend other than as officers of the New South Wales Department of Health?

DR LYONS: Well, it depends on whether or not they were invited there to commit the – the New South Wales Health system to certain actions or to contribute from

their knowledge, expertise and – and the fact that they were involved in service delivery and could be - - -

COMMISSIONER SACKVILLE: That might go to the extent of their authority, but it doesn't go to the status or capacity in which they've been invited, does it?

5 DR LYONS: I need to – I would need to - - -

COMMISSIONER SACKVILLE: Is that too fine a distinction?

MS FURNESS: Might I just assist, Commissioner. I think there's confusion between the two roundtables. At one there were no New South Wales people present, according to paragraph 91, and in the second there was. So they were

10 only - - -

COMMISSIONER ATKINSON: We understand that.

MS FURNESS: - - - present at one. Well, I'm sorry. I thought the question was directed to - - -

15 COMMISSIONER SACKVILLE: No, no, my question was directed to the 2018, referred to in paragraph 94, which suggests there were two representatives there.

DR LYONS: So there is confusion, because there were two roundtables, one in '19 and one in 2018.

MS EASTMAN: And I apologise. I had finished with the 2018 one and I was going to the 2019 one.

20 COMMISSIONER SACKVILLE: I understand, but I still had a question. Carry on.

MS EASTMAN: Okay. Commissioners, I suppose I should have asked you before I left 2018 and went to 2019, are there any questions or issues the Royal Commissioners have in relation to the National Roundtable on Mental Health of People with Intellectual Disability from 2018?

25 COMMISSIONER SACKVILLE: You're finished with the chart - - -

MS EASTMAN: Yes.

COMMISSIONER SACKVILLE: - - - that is presently before Dr Lyons, are you – have you?

MS EASTMAN: Yes.

COMMISSIONER SACKVILLE: Some of the things in that chart, I take it, are initiatives that have been started within the Department of Health prior to the Roundtable of 2018; is that correct?

DR LYONS: That's correct.

5 COMMISSIONER SACKVILLE: Yes. Okay.

MS EASTMAN: All right.

DR LYONS: So I – I would – I mean – and this is only my assessment of what the Roundtable might – but I suspect it was about learning what is going on across the system and then getting some consensus about what could be included into
10 improving things nationally. So I suspect that some of the reasons the two people went was because they were aware of the initiatives that we were actually undertaking and were contributing – contributing those to the process to enable that assessment to be made.

COMMISSIONER SACKVILLE: Thank you.

15 MS EASTMAN: So I'm now going to come back to August 2019. So this is the initiative of the Commonwealth Minister for Health. So there was a Roundtable on 2 August 2019. And New South Wales Health did not participate in that roundtable; is that right?

DR LYONS: That's correct.

20 MS EASTMAN: But there will be a further roundtable, as part of that process, in April this year. And are we right in understanding that you have been, or New South Wales Health, has been invited to participate in the next meeting?

DR LYONS: That's my understanding, yes.

MS EASTMAN: All right. With respect to New South Wales Health's position on
25 this Commonwealth initiative, you haven't addressed that anywhere in your statement. What is the expectation of New South Wales Health with respect to this Commonwealth initiative? What do you expect to come out of this process? And then I'm going to ask you what is that likely to mean for the delivery of health services for people with intellectual disability in New South Wales?

30 DR LYONS: So, just to expand on my response to the Commissioner, I think these processes usually are a way to synthesise activities, to learn what is being done across the country, to gain advice from experts who are working in the field about what should be done, and then to come up with a roadmap or a series of initiatives that are proposed to be committed to nationally that will improve how we provide
35 care. And then the States and Territories look at those recommendations and work

out how they will implement those recommendations, based on their relative starting positions.

5 So we would be having input into that process and contributing the things that we think are important, the things we're doing, things that we think are adding value, highlighting areas that we think more could be done. And then, through that process of synthesising, coming to an agreement, having a consensus about what is important to do, then prioritising those suggestions into a roadmap with timeframes and deliverables that we would then assess and sign on to.

10 MS EASTMAN: That sounds like something that's off into the future, not presently being done; is that right?

DR LYONS: Well, the roadmap might be an amalgam of things that are already being done. May not be being done everywhere, but there's a desire to actually ensure that they are being done. So it's an example of taking things that might be good, initiatives, innovations, developments that are occurring, may be done in 15 pockets, but saying we think they need to be done more broadly. Evidence that's emerged. You know, so there's a whole range of things that we've brought to bear to think, "Well, what should be done differently?" That's my understanding about how these processes work

MS EASTMAN: But you're aware, aren't you, that it's still early days for the 20 development of a particular policy or framework or whatever language you want to use for it. But the idea is that there are a number of elements – I think 10 elements – that identify short term, medium term and long term, covering a one to two year period, a three to four – or three to five year period and then a six to 10 year period. You're aware of that?

25 DR LYONS: I've seen a document with those timeframes on it.

MS EASTMAN: All right. And what work has New South Wales Health done in relation to those elements thus far? Has there been any action taken by New South Wales Health?

30 DR LYONS: So we've got a whole range of things that we are doing and have done to support improvements. I highlighted earlier some of the examples of innovation tools/resources that have been produced by the Agency for Clinical Innovation Disability Network. Those are available for the system. There are a whole range of supports that we've provided to our services to enable them to provide care more effectively and to have the capability of the clinical services raised.

35 We have invested in the Intellectual Disability Mental Health Hubs that I talked about, one for paediatrics, that will be centred around the Sydney Children's Hospital network, another one for adults that will be provided by Sydney Local Health District and Concord Hospital. Those will have State-wide responsibilities to support clinicians who are providing care in the mental health space for people who

have intellectual disability, as well, and ensuring that they can provide appropriate care and be supported to do that.

In relation to the general services, we have had Intellectual Disability Health Services Specialist Teams that have been established and tested in this State.

5 Probably three or four years ago they were established. There were three services initially. About 18 months ago, we committed to expanding those to six specialist teams. Those are in districts around the state and have responsibility for connecting – supporting people who are admitted to our services or receiving care in our services directly by actually providing supports - - -

10 MS EASTMAN: But – sorry to interrupt. Those initiatives are already existing in New South Wales. And I’m sorry if I wasn’t clear in my question. I want to know what has New South Wales done specifically, since you’ve become aware of this Commonwealth initiative in August, to focus on how New South Wales may fit into this scheme led by the Commonwealth.

15 DR LYONS: So those are - - -

MS EASTMAN: Not what you’ve already done, but what you’re going to do.

DR LYONS: So those are examples of things that will be in the roadmap in the future. We’re already doing them. That’s my point. So those are examples of the things that have been highlighted in the roadmap to be future-facing. Actually, 20 they’re already – already being done in New South Wales. So that’s what I was trying to highlight, is that – is that the - - -

MS EASTMAN: So that sounds to me like New South Wales doesn’t need this roadmap, because you’ve already got it in place.

DR LYONS: Well, that’s not what I was saying. What I was saying is that the 25 relative starting positions of each of the States and Territories may be very different, but having a National Roadmap would be about how do we raise the whole of the nation. So there’ll be – you know, as always with things, people will be at different places at different times. And so the good thing from New South Wales’ point of view is many of the things – and we may well have contributed to some of those in 30 the development of the roadmap or the – so – so we are already well advanced with many of them.

MS EASTMAN: Do you see - - -

COMMISSIONER SACKVILLE: Ms Eastman, it would be convenient to have a short break, either now - - -

35 MS EASTMAN: Of course. Yes. Sorry.

COMMISSIONER SACKVILLE: - - - or within a few minutes, whatever suits.

MS EASTMAN: Of course. Now is a convenient time.

COMMISSIONER SACKVILLE: We'll take a break for 10 minutes.

ADJOURNED

[11.06 am]

5

RESUMED

[11.29 am]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: Commissioners, we were dealing with the national
10 Commonwealth initiative roadmap just before the break. And over the break we've
been able to assemble some hardcopies of the policies that I was starting to deal with
a little earlier. So, Dr Lyons, we might go backwards, if you can bear with me, to the
policy. So can I take you back to paragraph 44 in your first statement. And you will
15 recall earlier that we were looking at some particular policies and I identified the
ones that I want to deal with. So I might just, in order, ask you to now have a look at
the policy which is identified in your statement at paragraph 44(n), the New South
Wales Disability and Inclusion Action Plan. So we'll provide a copy to you if you
need a hardcopy.

DR LYONS: Thank you.

20 MS EASTMAN: And, Commissioners, I understand you have access to it
electronically. But if you need a hardcopy, please let us know. It's in tender bundle
D behind tab 72.

COMMISSIONER SACKVILLE: Which tab was that, please?

MS EASTMAN: 72.

25 COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: Dr Lyons, I only need you to look at the document, nothing on
your iPad. You can put your iPad to one side. Do you need it to answer questions?

DR LYONS: I have some material that is useful to reference on there.

30 MS EASTMAN: Well, I'd prefer if you could listen to the questions that I ask you,
rather than check on your iPad.

DR LYONS: Certainly.

MS EASTMAN: And if you're not sure and you don't know an answer to a question, just let me know.

DR LYONS: Certainly.

5 MS EASTMAN: Now, are you familiar with the Disability Inclusion Action Plan 2016 to 2019.

DR LYONS: I have it in front of me, thank you.

MS EASTMAN: Right. Were you involved in any drafting of this action plan?

DR LYONS: I wasn't, no.

10 MS EASTMAN: And have you been responsible for any of the implementation of the action plan?

DR LYONS: My team are responsible for regular reporting on progress. So each year we will ask the Local Health Districts for progress and provide a report on their progress in relation to the components of the plan.

15 MS EASTMAN: Are you personally responsible for any implementation of this action plan?

DR LYONS: Not to my knowledge, no.

MS EASTMAN: All right.

COMMISSIONER SACKVILLE: When did you first see this action plan?

20 DR LYONS: I've seen it previously. So it's a document that's existed now for a number of years in the Ministry of Health.

MS EASTMAN: All right. Can I ask you to turn to page 9. And this is under the heading Guiding Principles. And there's a reference there to a guiding principle described as a culture of person-centred care. Is that a particular expression of art or a technical expression used within New South Wales Health?

25 DR LYONS: Person-centred care is used in New South Wales Health quite extensively, but it's also used in relation to how care is delivered in health care systems.

MS EASTMAN: What does it mean?

30 DR LYONS: It means not just providing care in the way you've been trained to provide care, but to contextualise that to the individual's circumstances and to reflect that not everybody is the same. So that we need to think about, as clinicians

providing care, what does that mean when we see a person in a clinic or a hospital bed or an emergency department situation, what do we need to reflect on to ensure that when we provide the care it's reflecting the needs of that individual, their family and their carers.

5 MS EASTMAN: Can you give me a practical example, so that I can understand what you mean by that.

DR LYONS: So an example would be when you're seeing a patient, who has come with a particular clinical condition, thinking about what care should be provided in the context of that individual's personal circumstances and how you might modify or
10 tailor what you would do for a response to that particular condition to the individual and their own circumstances. So it comes to, you know, what care's provided in what setting.

So, "Is this something that I should, as a clinician, decide to do here in hospital while they're still in hospital or could it be done out in the community?" What sort of
15 supports do they have as a family? You know, do they live alone and do they have a family who's there to care for them, as well? What age are they? You know, are they able to function effectively in terms of activities of daily living and those sorts of things? That then impacts on what care is provided in what setting, what follow-up should be delivered. It even could come down to things like how you
20 communicate and what processes that you use to ensure that people are involved in their care appropriately. Now, this is an issue.

Why it's highlighted is because as a health care system we continually strive for this to be done more effectively. And when we hear from people about when their
25 experiences are not as good as they could be, often it's around the fact that they were treated not – they don't feel that they were treated as a person, they don't feel that their personal circumstances were acknowledged. They feel like they were treated as a – sometimes they reflect that as a disease process or a condition, rather than actually feeling about them as a person.

And it's a tendency that we seem to flip into in health, because we're very
30 scientifically focused and we have approaches around biomedical models of disease and applying evidence into practice and using the literature and technology and all of those things that we're bombarded with. But we've got to remember always that there is a person there in front of us, and the person is the most important thing and we've got to think about all of that knowledge that we have and apply it in the
35 context of that individual and their own circumstances.

And that's a challenge, sometimes, to ensure that it happens consistently and appropriately, not just in our busy hospital emergency departments and beds in
wards, but even in what happens outside of hospital. So it's a focus because it is an issue that we need to continually reinforce and acknowledge the importance of and,
40 when it doesn't happen, address it as much as we can. But we recognise that's an ongoing challenge.

MS EASTMAN: What does a culture of person-centred care mean with respect to patients presenting with intellectual disability? And I asked you for a practical example. If you can give me a practical example for a person with intellectual disability?

5 DR LYONS: So it might be about how, as I was alluding to, the extent to which we tailor our responses to assessment and communication. And we've had - - -

MS EASTMAN: Let me ask you. If a patient presents with Down syndrome, could you give me a practical example of person-centred care approach for a patient presenting with Down syndrome in an emergency department. What should that
10 look like?

DR LYONS: So I'm a person who has not worked clinically for 30 years. And so to say what exactly should occur in an emergency department situation is not necessarily something that I am directly - - -

MS EASTMAN: Okay.

15 DR LYONS: - - - involved in.

MS EASTMAN: I'm not – let me - - -

DR LYONS: So I'm thinking about system level issues.

MS EASTMAN: I'm not asking you as if you were an emergency physician. But I'm asking you, from a policy perspective, what is your expectation, applying a
20 guiding principle of person-centred care, for a patient presenting with Down syndrome in an emergency setting. What does person-centred care look like for the person coming to the hospital in those circumstances?

DR LYONS: So it would start with the fact that for a person with Down syndrome, I mean, they might have a carer with them who needs to be with them at all times.

25 And so, whereas, you know, in the situation where we take someone into a clinical environment, often family are asked to stay in the waiting room. The first thing would be to say that we ensure the carer comes with them into the clinical space for that assessment. These are tailoring our approaches to what we do to the circumstances of the individual.

30 Ensuring that we don't just ask questions to the carer, but also direct questions to the person that we're caring for and not assuming that they can't answer them. These are the sorts of examples that in practice what that means and what we hear from time to time doesn't happen. There are assumptions made or people move to
35 situations, because they don't think about the implications of being person-centred in everything that they do.

MS EASTMAN: Well, that sounds to me like person-centred is an issue around communication; is that right?

DR LYONS: It will be one element of it, yes.

MS EASTMAN: And what other elements might you expect to see?

5 DR LYONS: So it will be about if there are procedures to be undertaken, recognising that that person may have not understood what's happening, and taking extra steps to explain things simply.

MS EASTMAN: That's also communication.

DR LYONS: All right.

10 MS EASTMAN: Anything other than communication?

DR LYONS: Having people who are present to reassure them, because they might have some underlying anxiety about what's happening, so having somebody there to be a presence, to reinforce that it's okay - - -

MS EASTMAN: A medical person, someone in a hospital setting, or somebody
15 else?

DR LYONS: A carer, somebody, a family – you know, a person who's familiar to them that they may feel more at ease with. It will come to, you know, how investigations are undertaken and the way they're being undertaken to ensure that there's some support for them through those processes. Each individual will need to
20 be assessed – and then it will come down to the treatment and what treatment is offered and how that's delivered.

MS EASTMAN: Okay. So this is one of the policies of New South Wales Health that you expect to be implemented through the Local Health District and then down to the frontline delivery of services; is that right?

25 DR LYONS: Certainly. It comes right down to where care is received right through our system.

MS EASTMAN: And during the course of the life of this particular strategy, which is 2016 to 2019, what specific measures can you tell the Royal Commission have implemented the culture of person-centred care at that very frontline delivery? What
30 has come out of this strategy that we can see at the coalface, so to speak?

DR LYONS: So I probably need to make the point that not – there is not a direct relationship between – and, as I think we've highlighted in some of the questions that have come to me about policy directives, guidelines, and so forth, about having intersectional and cross-cutting issues, as well - - -

MS EASTMAN: Sorry. What does intersectional crosscutting mean?

DR LYONS: Well, it means that there are a broad – so the issue around person-centred care doesn't just apply to this policy; it applies to a whole range of other policies that we have in place. So we have strategies – we have a whole lot of actions about how we support clinicians to be more person-centred that don't just come out of this policy, but they come out of a whole – you know, there's a focus on this at a range of different levels within the system. And so we have, you know, a whole agency, as I said, the Agency for Clinical Innovation, supporting approaches to be more person-centred as a part of what they do; the Clinical Excellence Commission, which has as part of its focus around how we do these things and how we support clinicians to do this more effectively. We have - - -

COMMISSIONER SACKVILLE: Dr Lyons, I know you're very keen to tell us that there are a range of measures in place, but I wonder if you could pay attention to the question that's being asked and answer that question. Perhaps, Ms Eastman, you could ask the question that was directed to Dr Lyons.

MS EASTMAN: I apologise if my question was oblique, but all I wanted to know was - - -

COMMISSIONER SACKVILLE: I wasn't implying that it was oblique.

MS EASTMAN: All I wanted to know was, looking at this guiding principle of person-centred care, can you tell the Royal Commission of any specific measure that implements that policy on the frontline, at the coalface, whatever you wish to call it. What's come out of this policy that we can see implementation on the frontline?

DR LYONS: And, unfortunately, as I said, trying to explain, that it's not as simple as just looking at what is in this policy and seeing a direct relationship to that, to what happens to how care is delivered for a patient. There are many things that we do across the system that will support this policy and other policies around patient-centeredness.

MS EASTMAN: Is it fair to say that you can't identify any particular measure? Is that right?

DR LYONS: No. I would say that there are many measures, but they don't necessarily specifically relate to this policy.

COMMISSIONER SACKVILLE: What's the best one - - -

DR LYONS: Well, can I - - -

COMMISSIONER SACKVILLE: Best measure that you can identify.

DR LYONS: Can I take that on notice about that. Examples of the things that we're doing. But what I will say is that we measure patient experience in our system all of the time. We have processes for complaints or concerns to be raised if people don't feel that there's effective care being provided.

5 MS EASTMAN: No. I'm trying to ask you what measures have been implemented, not what's failed or which has resulted in a complaint, but something practical.

DR LYONS: So - - -

10 MS EASTMAN: And I'm asking – I'm asking you from the perspective of somebody coming to the hospital with an intellectual disability. They might have read this plan and they might have said, "If we're expecting person-centred care when we turn up to our local hospital", what can they say their experience has been based on this policy and the implementation of policy? That's what I'm asking you.

DR LYONS: Well, let me take that and we'll investigate it and provide the Royal Commission with our response.

15 MS EASTMAN: All right. The responsibility for implementing this plan is set out at page 13. And there's a group called the DIAP Governance Group. And that is said to be:

A group to drive implementation of this plan, publish an annual update for internal and external stakeholders.

20 And then, in terms of monitoring and reporting, at page 29 of this strategy and plan:

This group will guide the implementation and monitor progress.

And it's:

25 *Chaired by the Integrated Care Branch, who will assume responsibility for the production and publication of an annual update for internal and external stakeholders.*

Have there been annual updates, both internally and externally, published in relation to this policy?

DR LYONS: There have.

30 MS EASTMAN: There have?

DR LYONS: There have.

MS EASTMAN: And what is the outcome of those updates? What can they tell us? Are you aware of them?

DR LYONS: Well, I haven't seen one recently, but I've seen them as they've come through the reporting process. It's usually an annual reporting process that we provide. And what it would look at is the sorts of actions that are recorded in the plan and then talk about what progress has been made in relation to those actions across the system. And would highlight any things that we would want to, you know, identify as being examples of where those have been implemented effectively and what that has meant.

MS EASTMAN: All right. You can't, offhand, think of any particular aspect of any of these reports that identified any particular measures, for example; is that right?

10 DR LYONS: I haven't looked at one recently. So I – I would provide you with that information after assessment.

COMMISSIONER SACKVILLE: Dr Lyons, who is the most senior person within the Department who has got major responsibility for developing policy and supervising the implementation of policy relating to health care for people with cognitive disability?

15 DR LYONS: That would probably be my position - - -

COMMISSIONER SACKVILLE: Is it?

DR LYONS: - - - because I have responsibility for both integrated care branch and also - - -

20 COMMISSIONER ATKINSON: But you don't seem to have been prepared properly to be able to answer the questions on health care for intellectually – people with intellectual and cognitive disabilities when you've come to give evidence.

DR LYONS: I'm answering the questions the way – the best I can. I – I would say to you that there are a lot of responsibilities for anybody in – in Health. And we have very clear responsibilities about certain components, but we rely on others to assist us. So I have a team of people who help me with these things. And I've been briefed about things and prepared, but there are very detailed questions being asked, when there are many things that I have responsibility for. So I'm very happy to take that information on notice and provide it.

25 COMMISSIONER SACKVILLE: That's why I asked you who would be the best person placed to answer them from his or her own knowledge. Is there such a person?

DR LYONS: One individual?

COMMISSIONER SACKVILLE: Yes.

35 DR LYONS: As I've said, we have a range of people who are responsible.

COMMISSIONER SACKVILLE: You have a range, okay.
COMMISSIONER ATKINSON: So is the answer no?
COMMISSIONER SACKVILLE: Okay.
COMMISSIONER ATKINSON: So the answer to that is there is no person who is
5 better placed to answer these questions than you?
DR LYONS: Not to my knowledge.
COMMISSIONER SACKVILLE: Yes, Ms Eastman.
MS EASTMAN: Can I ask you now about the policy identified at paragraph 44(x),
which is the Service Framework to Improve the Health Care of People with
10 Intellectual Disability. And, Commissioners, you will find a copy of this at tender
bundle part D, tab 46 in volume 3. And we have a copy for Dr Lyons.
COMMISSIONER ATKINSON: So it's attached to paragraph 44?
MS EASTMAN: So it's – the reference in Dr Lyons' statement is page 11 of 27 in
44(x).
15 COMMISSIONER ATKINSON: Thanks.
MS EASTMAN: In your tender bundle, part D, tab 46.
COMMISSIONER ATKINSON: Thanks.
MS EASTMAN: All right. And Dr Lyons, you've just been handed a copy of this
document. So you're just looking at that now. Is this something that you're familiar
20 with, the Service Framework?
DR LYONS: Not in detail, no.
MS EASTMAN: Were you involved in drafting this document?
DR LYONS: No, I wasn't.
MS EASTMAN: Do you have responsibility for the implementation of this
25 document?
DR LYONS: I would have to assess – there will be components of it that I have
responsibility for. Yes.
MS EASTMAN: Are you able to say, just glancing through it, which components
you have responsibility for and which you don't?

DR LYONS: So examples like the Specialised Intellectual Disability Teams, I have responsibility for. There will be others that – strategic health policy, those areas. Yes.

5 MS EASTMAN: So I – can I just make this clear: I am assuming that, as with the Inclusion Action Plan, which was 2016 to 2019, that if you’ve identified a policy in paragraph 44, that they continue to be ongoing policies notwithstanding their dates. So I’m making that assumption.

DR LYONS: That’s a correct assumption.

10 MS EASTMAN: And so with respect to the Service Framework to Improve the Health Care of People with Intellectual Disability - - -

DR LYONS: Mmm.

MS EASTMAN: - - - this is a document that bears the date July 2012. And so do we assume that seven and a half years into it, that this continues to be the Service Framework? Has it been – and perhaps I will – if I shortcut it, has this been updated, reviewed or evaluated at any point in time?

15 DR LYONS: Not to my knowledge, no.

MS EASTMAN: Well, why not?

DR LYONS: Well - - -

MS EASTMAN: I think you said earlier that you review and update policies as they’re being reported back in - - -

20 DR LYONS: It may – it may have been, but what I’m saying is not to my knowledge because I’ve been in this role for the last three years. I don’t know whether there was anything done before I was appointed to this role.

MS EASTMAN: I – and if you’re not aware and you don’t know, please let me know. But if you look at – and if we just use the executive summary on page 2, this Service Framework is based on a tiered model of care, tier 1 through to tier 5. Is that something that you know about?

DR LYONS: I have knowledge of tiered levels of service deliver. Yes.

30 MS EASTMAN: And in terms of – and we will get to this and I know you’re keen to talk about some current initiatives in terms of the specialist teams and the Hubs – how do these tiers operate at a practical level and at a Local Health District for the care of people with intellectual disability?

- DR LYONS: So it's the principles of, you know, having an approach to population health and initiatives that might be considered for a population as a whole or a subset of the population, being the tier 1 responsibilities and then the fact that, when people then access care, they will do that initially usually through – in a community setting through contact with the general practitioner or community health service; that's the sort of tier 2. And then it continues into areas of more complexity and specialisation. So tier 3 is acute health services. So if you're acutely unwell, you might turn up to an emergency department for care and then be, potentially, admitted to hospital depending on the assessment that's made.
- 10 And then you have supporting highly specialised services. That would be established – that would provide advice to other teams that might be involved in providing care. So that's when you get into these highly specialised services, like the Specialised Intellectual Disability Health Services. And then the tier 5 is around how you provide clinical leadership and overarching direction. So it's an example of – of starting off on the broad and then moving into more highly specialised. Each time – those services might be not everywhere, but the idea is that across our health system we connect people up to ensure that if they have needs that they're connected to the right part to get that care or be supported appropriately.
- 15 MS EASTMAN: All right. Look, again, I'm just going to use the executive summary, if that's convenient, but the executive summary opens with these words:
- 20 *People with intellectual disability have poorer health outcomes and greater difficulty obtaining health services in comparison with the general population. They experience a high prevalence of significant medical problems and the health conditions are often unrecognised, misdiagnosed and poorly managed.*
- 25 So that should come as no surprise to anybody, even back in July 2012; is that right?
- DR LYONS: Well, that's the opening statement. It's - - -
- MS EASTMAN: You don't disagree with that, do you?
- DR LYONS: No, I don't disagree.
- MS EASTMAN: And is it the case that, if one looks at this particular Service Framework to improve the health, that what New South Wales was seeking to do back in 2012 was to work on the basis of an acceptance that people with intellectual disability have poorer health outcomes and greater difficulty, and to then develop a way of integrating both the health and the disability services aspects to improve better health outcomes; is that right?
- 30 DR LYONS: It's – it's mostly around the approach we take within the health system to ensure that the particular needs are met and that we can address the shortcomings that have been identified in that first paragraph.
- 35

MS EASTMAN: All right. At page 18 of the document, under the heading Governance and Reporting, it suggests that:

5 *New South Wales Ministry for Health will lead the planning and implementation phases of the Service Framework, working in close collaboration with the Department of Family and Community Services, Ageing, Disability and Home Care.*

So do you have any knowledge of there being an advisory group which is identified in the following paragraph? And can I ask you is the advisory group representatives of the various government departments?

10 DR LYONS: Yes. So – so in the time I’ve been in the role, what has transpired is we’ve moved into the establishment of the National Disability Insurance Scheme. And New South Wales was one of the first States to progress implementation of that scheme for its citizens and community. And there has been very active involvement – what’s happened is that this Framework has been subsumed by the fact that we’re
15 actually involved in the changes, and that has been the major focus over the last three years. And there has been - - -

MS EASTMAN: Is this still the Framework then?

20 DR LYONS: Well, the Framework still exists, but it’s now in the context, as you’ve quite rightly pointed out, that ADHC is no longer operating as the service provider, that we’re now operating with many service providers in the National Disability Insurance Scheme space. So the whole move to how we responded to that was a really important component of how we delivered, effectively, care to people with intellectual disability.

MS EASTMAN: So what’s the current status, then, of this Framework?

25 DR LYONS: The Framework still exists and we’re working – and just to come back to complete my answer – there have been very regular meetings with Department of Communities and Justice (FACS), Education, Transport, as we have been implementing the changes with the establishment of the National Disability Insurance Scheme about what that means for health in the context of the things that
30 we do, but also with all of the other agencies, to ensure that we can meet the commitments that have been provided in this Framework. And we’ve been working very hard to ensure that, as those changes occur, we continue to strive for this framework. And we’ve been continuing to invest in the services that are highlighted in here – highlighted. And I know you’ve mentioned a couple of times that we’re
35 going to get to the intellectual disability - - -

MS EASTMAN: We are.

DR LYONS: - - - Hubs. I’ve tried to talk about those positive aspects of what we are doing, because they do recognise that we have much more that we need to do;

that we are recognising that we need to invest in providing more supports; that we do need to think about how we do that in a way that allows people who are receiving care, whether that's in a community health service, a clinic, in an emergency department, in a hospital bed, all of them can have access to supports and knowledge and expertise that enable them to get better care and have better health outcomes.

5 And this is not easy to do in an – in an organisation that's as large as New South Wales Health. So – so I'm highlighting the importance of continuing to focus on it, but that we are doing things and we are recognising the need to do them all.

10 COMMISSIONER SACKVILLE: As I understood your answer, you were suggesting that the introduction of the NDIS and the transfer that that implies of some services from State to Commonwealth responsibility, has some impact on the way in which health services in hospitals are delivered. But what does the NDIS have to do with the quality of care delivered within hospitals to people with intellectual disability?

15 DR LYONS: It is an issue around how we support the change from ADHC who was a provider in the government space, to the other providers that now exist, and then what that means for health care that's delivered. And it might come to what support is provided to somebody who's being supported to live in a residential accommodation under disability care and who comes to help with communication.

20 For instance, if somebody's got communication difficulties in a hospital setting. Those sorts of things.

COMMISSIONER SACKVILLE: The point of my question is that the introduction of the NDIS is obviously an extremely important initiative and involves some substantial changes in the role of the State for all sorts of reasons, as you're no doubt familiar with. But rather than rendering this particular policy dormant, which seems to be its current position, on one view it – the introduction of the NDIS just increases the urgency of implementing this policy within that part of the health system that is concerned with the delivery of services within a hospital setting.

25 DR LYONS: I agree with you. And I would say that this is not - - -

30 COMMISSIONER SACKVILLE: Well - - -

DR LYONS: I would say this is not dormant.

COMMISSIONER SACKVILLE: But you – I thought you just said it was. That's my word, "dormant". You said it's not presently active, effectively.

DR LYONS: This Framework?

35 COMMISSIONER SACKVILLE: The 2012, yes.

DR LYONS: Well, I'm sorry. I didn't think I'd said that.

COMMISSIONER SACKVILLE: Didn't you?

5 DR LYONS: But I might – what I was saying is that we had focused our attention in the group that was being mentioned in the framework around the move to the NDIS. I indicated this framework still exists. And we've actually invested in it with the Intellectual Disability Teams that have specialised functions and networks. So, I'm sorry. I will stand corrected if it came across that way, but it – it's certainly not saying this is dormant. It's still being invested in and we still have this as a framework.

COMMISSIONER SACKVILLE: Yes.

10 MS EASTMAN: One final question, coming back to the 2012 document. At page 19 under the heading Performance Indicators and Evaluation it says:

An evaluation strategy for the Service Framework will be developed – and – will include the development of key milestones and performance indicators as a whole and mechanisms for consistent regular reporting against these performance indicators that can be incorporated into existing New South Wales Health and ADHC reporting requirements.

15

Do you know if that ever happened?

20 DR LYONS: Let me take that on notice. But what I will say is that we have been monitoring many indicators around the care that's being provided for people with disabilities, generally, as a part of the changes that have been occurring with the move to the new service arrangements. And, in particular, I will talk about the fact that we, as I said earlier, established those Intellectual Disability Hubs to provide service. They were extensively - - -

25 COMMISSIONER ATKINSON: Excuse me. Dr Lyons, it would really assist us – it would certainly assist me – if you answer the question Ms Eastman asks. I know you want to get on to something else, and she is aware of that and we're very aware of it. But the question has been asked for a specific purpose. So if you would just answer the question and then we can go on to the next one, it would certainly assist me.

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DR LYONS: I'm sorry. I thought I said I would take that on notice.

MS EASTMAN: Take – all right. Okay.

DR LYONS: And then I – and then I gave some explanation of other things that we had evaluated, but I will take that question about the specifics on – on notice.

MS EASTMAN: All right. So in relation to that question of evaluation and monitoring, what I wanted to ask you further in relation to that is in paragraph 44 subparagraph (v) you refer to a policy called responding to needs of people with disability during hospitalisation. And I will give you a copy of that. Because this
5 speaks to – about a particular program in relation to collection of data and monitoring. And I wanted to ask you – you might need an opportunity to have a look at that. But I want to ask you whether this is the type of evaluation program that was contemplated in the Service Framework.
So I know it's tricky – and, Commissioners, part of what I'm trying to understand is
10 how all of these New South Wales' policies work together. So we've gone – as I said, we have gone through each of the policies and tried ourselves to understand the interaction, but Dr Lyons, I'm going to need your help in understanding that what we think matches together is in fact the right match. Commissioners, this is in tender bundle part D behind tab 176.
15 COMMISSIONER SACKVILLE: Thank you.
MS EASTMAN: So, Dr Lyons, are you familiar with this document?
DR LYONS: I am.
MS EASTMAN: And did you have a role in drafting this document?
DR LYONS: No, I did not.
20 MS EASTMAN: All right. And do you have a role in the implementation of this policy?
DR LYONS: I do.
MS EASTMAN: And this is a policy directive. So this is the high-level compliance document; is that right?
25 DR LYONS: That – that's correct.
MS EASTMAN: Okay.
MS EASTMAN: Now, in relation to monitoring, at page 23 of 44, there's a reference to monitoring. So can you just take a minute just to have a read of that. And read it to yourself. And then, over the page, you will see there's a heading that
30 says Performance Indicators, Outcome Measures and Patient Experience. Have you got that?
DR LYONS: Mmm.

MS EASTMAN: And that, in turn, refers to Appendix 1, Potential Performance Indicators and Outcome Measures, which is page 25. My question is, having regard to all of that material as a policy directive, has there been the collection of the data to identify the performance indicators and outcomes/measures described in Appendix 1? And, if so, where can we find that material? Where can we find a report outlining performance indicators and outcomes?

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DR LYONS: So a couple of points out of what's highlighted there is that there is an implementation checklist developed for use by Local Health Districts to assess their compliance with the policy directive; that's under "monitoring".

10

MS EASTMAN: But I – sorry.

DR LYONS: So – so – so they - - -

MS EASTMAN: Again, if I'm - - -

DR LYONS: They can use the checklist to monitor implementation. Then I'll go over to the performance indicators, outcome measures and patient experiences:

15 *LHDs, especially health networks, should develop mechanisms to determine if there's a difference in outcomes.*

MS EASTMAN: That's exactly what I'm focusing on.

DR LYONS: So – so that's at the Local Health District or specialty network level.

MS EASTMAN: So where can we actually find that information? Is this published or collected in a document?

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DR LYONS: We will need to go back to the Local Health Districts and ascertain to what extent they have applied this, and whether or not there's information available to report back on.

MS EASTMAN: Right. When I asked you earlier about the system of going with a policy down to a health district, and then coming back to a central point for review of the policy, would I be right in assuming that any data collected in the form of performance indicators, outcome measures and looking at difference in outcome for people with disability compared to the rest of the general population, would not be the type of information that would remain exclusively within a health district, but its very nature would be the type of information to come back to a central point for analysis as to a whole of New South Wales outcomes rather than just district by district? Wouldn't that be the case?

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DR LYONS: The challenge is, as I outlined in my earlier comments, that the data – the data capture doesn't allow easy analysis of that at the moment. Our systems don't allow us to easily identify people who are in our care with disability. And

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that's a big problem for us in actually ascertaining some of these measures. Whether or not the Local Health Districts have actually got around some of the – the fact that the systems don't accurately collect that, and have done some analysis to help with their reporting at the local level, I would need to go back and – and check that and see what we can provide you, but we certainly haven't got the ability to aggregate that at the system level easily.

5

COMMISSIONER SACKVILLE: Isn't this precisely the sort of thing that should be done at the State-wide level, that is to say developing methodologies for the uniform collection of data that can then be compiled and collated, and inferences drawn and policies developed?

10

DR LYONS: Yes, we would – we would certainly agree. And we've highlighted the need for better connections between what is happening in the disability space and the health space so that we can make those connections to ensure that we are able to look at the health outcomes for people who are in our care with disability.

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COMMISSIONER SACKVILLE: Well, as I follow your evidence, the implementation of the performance indicators requirement and outcome measures requirement is something left to the individual districts? Local health - - -

DR LYONS: It's because our systems don't easily enable us to capture it and assess it at the State level.

20

COMMISSIONER SACKVILLE: I understand. And it's precisely because your systems don't that I suggested that this is something that needs to be dealt at the State-wide level so that the systems do enable the capture the relevant information.

DR LYONS: We would agree and support that. I have been advocating for that.

MS EASTMAN: All right.

25

COMMISSIONER BENNETT: Dr Lyons, what is – just on the data scene, part of your remit is planning for the New South Wales health system. What do you think the implications are about good planning if you're having a problem having good data? You know, to – basic information about your population group, attendance at hospitals, readmissions. Is that the sort of data that you're missing?

30

DR LYONS: We have that information for people, but it doesn't go down into particular subgroups very well sometimes. So it – the extent to which we can actually go down into smaller groups within that, we've got – we've got high-level information about everyone who comes to our services, but to – to know that they have intellectual disability is not necessarily captured every time, or any other disability for that matter. It's not routinely captured in a way that enables us to draw that information out of the systems easily.

35

COMMISSIONER BENNETT: And what is the impact on you planning the service delivery if you don't – if you've still got a gap in your richness of understanding the cohort that you've got plans and policies and Hubs for, if you – if you've not got precise information about the population.

5 DR LYONS: So it creates a challenge in how you would plan for what you need to do. But it's not the only thing that you would use in – in assessing what needs to change in terms of service delivery. Data is an important component, but there will also be analysis that might be undertaken by taking a cohort of that particular group of the community and actually assessing their particular needs by a survey, for
10 instance, or analysis of feedback that they're provided around accessing services at the moment, or outcomes that we – that we do have, either from the literature or from undertaking analysis at the local level. But it is an issue around a gap at the system level, there's no doubt.

COMMISSIONER BENNETT: And could that gap be that you can't accurately
15 forecast or, you know, within a reasonable good assessment, what the demand will be, and, therefore, what your level of services need to be and where they need to be located? Is there a lag time between the reality and adjusting because – because of the lack of data, that you can't actually use past collection of information that can allow you to forecast and plan for what a future state should be?

20 DR LYONS: It is a challenge and it does mean it is difficult to plan. I mean, that's one of the things that we have highlighted, the need for a way to connect the data systems that exist in disability care with the systems that exist in health care to be able to make an analysis about how we can provide care more effectively and to monitor service patterns and what we could do, if there – if there is a gap in service
25 delivery, how we ensure we get that addressed. So we've been advocating very strongly through the State to the national level to have a way to do that that is consistent and that we can apply at the State level as well.

COMMISSIONER BENNETT: We heard from a lot of witnesses – not just from
30 New South Wales – but how long they have to wait to get access to a service because the demand is higher than what the resources that have been invested. How do you plan that you're going to have this proportion of your population that is going to need those services and how quickly? When you look at one year and the next year, are you able to adjust the resources that are needed to deliver those services for those people that need them?

35 DR LYONS: Yes. It's the challenge for us in a health system, because the demands on our services always outstrip the ability to actually respond. There are – there are needs that are greater than – than the services available to deliver them. And there is a need to think about how – how we adjust and adapt by getting data, as an example, but also through feedback that we receive through particular patient groups about
40 whether they can access services or advocacy or research that gets published that highlights a gap. Those, then, are – then are all looked at and then we work out, within the resources we have, where can we invest further to improve the care.

So – so an example of that is, you know, where we have made investments. And in the evidence I’ve provided there are examples of where, in New South Wales over the last few years, we have put more money into how we support people with intellectual disability. We are investing in how we can make improvements in people with intellectual disability and mental health problems. Those are concrete examples of where we have prioritised as a result of identified need. So – so we are doing things. And I acknowledge we can do a lot more. I appreciate that. But I – but I – I feel like it’s important to acknowledge that the – there is work that is being – has been committed to that we are doing; that we’re advocating for more, not just at the State level, amongst our colleagues in agencies in New South Wales, but at the national level. So we do recognise the need and we’re conscious of it. Sure, we can do better. But we are taking active steps to see how we can improve care.

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: Dr Lyons, throughout the course of the hearing, a reference has been made on a number of occasions to a publication and some work done by the Agency for Clinical Innovation. And this is the same agency that developed the guidelines on research that you’ve got in paragraph 44(f).

DR LYONS: Mmm.

MS EASTMAN: And it’s a document which, in shorthand, has been called The Essentials. And, Commissioners, a copy of this is in the tender bundle at part D, tab 24. It’s got the coloured peacock on the front. Dr Lyons, we’re going to give you a copy but it doesn’t have the colour, but we will - - -

DR LYONS: I will make do. Thanks.

MS EASTMAN: You will be able to follow it. Now, this is a document that you haven’t listed in the policies in paragraph 44 of your statement. Is this a document that you’re familiar with?

DR LYONS: I am.

MS EASTMAN: And can you tell us why it’s not included as one of the policies?

DR LYONS: Because the Agency for Clinical Innovation is one of what we call a pillar organisations, which is independent of the Ministry of Health, but has a responsibility for, as I outlined earlier, supporting – how we support clinical innovation and get evidence into practice and how we support improvements at the system level. So – so this group – and I – I highlighted, responding to the Commissioner’s question about some of the work of the ACI earlier, this is an example of one of the many pieces of work that they’ve developed to support improvements across the system.

MS EASTMAN: All right. But the Guidelines for – on Research Inclusive of People with Intellectual Disability, which you’ve identified in 44(f) - - -

DR LYONS: Mmm.

5 MS EASTMAN: - - - is a policy. But are you saying that The Essentials document, also prepared by the same agency, is not a policy?

DR LYONS: There’s no difference in the status of those, as far as I’m aware.

MS EASTMAN: Then why - - -

DR LYONS: These - - -

MS EASTMAN: Why hasn’t this been included?

10 DR LYONS: Then it may have been an omission from our point of view. Because there are many documents, as you saw, that have been produced across the system to support improvements. I think when people put the list together they probably looked at Ministry of Health – what they had on the Ministry of Health list.

MS EASTMAN: So it might have been an oversight to include The Essentials; is that right?

15 DR LYONS: Yes.

MS EASTMAN: Do you need an opportunity to look at that document before I ask you whether or not you would accept that this framework in The Essentials is a very important framework in relation to supporting people with intellectual disability access health services in New South Wales, and also building the capacity in New South Wales for people to access those services? So that might be through workforce, and the like. If you haven’t read it and you’re not sure, tell me.

20 DR LYONS: No, no, I can see – I can see it would be, absolutely, a very valuable tool to support implementing those changes into clinical care across the system.

MS EASTMAN: If you have a look at page 18, there are 10 guiding principles of quality health services for people with intellectual disability. And I don’t know whether you’re familiar with this or you’ve seen this document or the particular guiding principles.

25 DR LYONS: I - - -

30 MS EASTMAN: Take a moment. But I want to ask you how would this fit in with the other guiding principles in the documents that we’ve looked at: the action plan, hospitalisation policy, and the like.

DR LYONS: They would be completely consistent with supporting those. I don't see any dissonance at all.

5 MS EASTMAN: If this is a New South Wales policy, do you have any knowledge about how The Essentials have been used at a Local Health District? And you may not know. And if you want to take that question on notice and provide us with some further information, I'm happy for you to do that.

10 DR LYONS: So my understanding it is – it is being implemented in South Western Sydney, one of the Local Health Districts, at a district level. But having said that, the whole role of the Agency for Clinical Innovation were to provide tools and resources for system improvement. That can be taken up by anybody in the system at whatever level. So this being available, I would anticipate, means that, at a range of different levels across the system, whether that's a department of a hospital or community health centre or a clinic environment, there may well be people who are using this to support improvements in how they deliver care.

15 MS EASTMAN: All right. Just, finally, on the policies, is the Commission – Royal Commission right in understanding that these policies, directives, down through to guidelines, are publicly available through the website of Health; is that right?

20 DR LYONS: Anything that's on the policy, that list, would be available on our – it should be available on our website, as are the documents from the other agencies. They would be published - - -

MS EASTMAN: All right.

DR LYONS: - - - usually on their websites as well.

25 MS EASTMAN: And one issue that has arisen during the course of the Royal Commission's investigation, over the past week or so, is the accessibility of policies of this kind to members of the public and, in particular, families and people with intellectual disability. So that's arisen as an issue. Am I right in understanding that what you say at paragraph 98 of your first statement, at page 22 and following, sets out what you wanted to tell the Royal Commission about the accessibility of New South Wales policies for the general public, but also for people with intellectual disability, their families and carers?

30 DR LYONS: So in my first statement or my second statement?

MS EASTMAN: I'm still in your first statement.

DR LYONS: All right.

MS EASTMAN: So paragraph 98 is page 22.

35 DR LYONS: It's just that I have a lot of documents here now, so - - -

MS EASTMAN: I know. Well, would it help you if I took some of the documents that I don't need to ask you about away?

DR LYONS: It's okay. I'm good now.

MS EASTMAN: All right. Okay. Take your time.

5 DR LYONS: So paragraph?

MS EASTMAN: 98. It's at the bottom of page 22 under the heading Communication. I just want to understand whether we understand your evidence that these are the steps taken by New South Wales Health to ensure its resources and information – and that includes the policies – are provided or communicated in a

10 manner accessible to people with cognitive disability, their families and carers.

DR LYONS: So it states that we comply with the web content accessibility guideline when publishing content.

MS EASTMAN: All right. Now, I'm not sure that I understand what that means. And can you help me in relation to what that means in relation to making these

15 resources accessible to people with cognitive disability?

DR LYONS: So there's further evidence in the paragraphs following about - - -

MS EASTMAN: Yes.

DR LYONS: - - - the assessment and the technical assessment.

MS EASTMAN: Yes.

20 DR LYONS: And the levels.

MS EASTMAN: That looks like talking about writing and editing in plain English.

DR LYONS: So I will take that on notice about what further detail I can provide you in addition to what's in the evidence.

MS EASTMAN: Are you aware as to whether any of the policies and the ones that

25 I've specifically identified that we have put some attention on today, because we think those are the key policies – have any of those policies been developed in what is called Easy Read format? Do you know that?

DR LYONS: I will need to take that on notice.

MS EASTMAN: You're aware the Royal Commission, in making a request to the

30 Department to provide a statement, that we asked about policies in Easy Read. Are you aware of that?

DR LYONS: I will take it on notice about whether or not there's anything further I can provide on that.

5 COMMISSIONER GALBALLY: Ms Eastman, can I just add that I'm very interested in the policies for other population groups that people with cognitive disability would be part of. So I'm interested in all the policies, the women's, the violence, abuse, all the other policies too, to know about accessibility.

DR LYONS: Thank you. We will include that in our response.

MS EASTMAN: Right.

10 COMMISSIONER SACKVILLE: What's the precise status, Dr Lyons, of this Essentials document? Is it provided to Health Districts as, as it were, an aide-mémoire or helpful suggestions or does it have any greater status than that?

DR LYONS: So it's certainly as a resource to enable improvements. And it's an example of what we were talking about before, which is where people have ideas about how they could improve the care that's provided. Then we support the agency to establish a mechanism to look at the evidence, turn it into something that will help 15 people in delivering care to do it better. And then these resources are provided to the system.

The extent to which they're taken up is an issue around the prioritisation at the local level. The challenge for us is – across all of health is that this is one network of 35. 20 All of them are looking at things that they could do to improve care for particular aspects of care that we provide across our system. And so there is a huge amount of information being provided by the organisation to support improvements in care. And the ability to actually make those improvements at the local level is very much dependent on the fact that the teams need to see that as a priority or have some issues 25 that they're addressing, because their ability to do all of the improvements that might be available to them wouldn't be possible in the time they have available. That's the challenge for them.

COMMISSIONER SACKVILLE: So it's a matter, in essence, for the Health District to determine the extent to which it is able to and wishes to implement this 30 Essentials document, for example?

DR LYONS: That's correct.

COMMISSIONER SACKVILLE: Yes. The group that prepared this document, the ACI, Intellectual Disability Health Network, this consists of people who serve on the network in a part-time basis. Some are full-time officers in other health – in health 35 agencies, but it's an ad hoc group, isn't it?

DR LYONS: Yes. They're voluntary. So the groups are all voluntary, apart from the network manager, who is employed by the Agency for Clinical Innovation.

Everybody else comes from a position of wanting to make improvements in care. So they actually spend their time to do that, which is amazing, really, that we have so many people who do want to contribute possibly.

5 COMMISSIONER SACKVILLE: Well, there's some, obviously, eminent people on this group. And we've heard from a number of them who have given evidence. There are no people with cognitive disability in the group?

DR LYONS: I would need to check, because there are a – there are – the networks are actually very large.

COMMISSIONER SACKVILLE: Are they? I see.

10 DR LYONS: And the extent to which people are involved in the development of tools and resources depends on, you know, what they might be interested in doing in their capacity to be involved and the time - - -

COMMISSIONER SACKVILLE: I'm just looking at the list.

DR LYONS: But the networks can be - - -

15 COMMISSIONER SACKVILLE: Sorry. I'm just looking at the list - - -

DR LYONS: So that would be – they may just

COMMISSIONER SACKVILLE: Sorry. Can I finish. I'm just looking at the list of people acknowledged on page (iv). But that's all right. If you need to check on that, by all means. Thank you.

20 MS EASTMAN: I just want to ask you some very brief questions about training. You've dealt with this in your statement at page 20, paragraph 77 and following. Have you got that? Still in first statement. And I think you say the number of courses reflect the fact that the training needs vary substantially across New South Wales Health. So I want to just come in and focus on training in relation to health care needs of people with cognitive disability. And at paragraph 79 you've said:

25 *Local education and training initiatives, directly and indirectly relating to disability, are used in addition to State-wide resources.*

And then you've listed a number of documents. And I think they're all Excel spreadsheets. Have you looked at those documents identified in paragraph 79 before giving your evidence this morning?

30 DR LYONS: I haven't seen those spreadsheets, no.

MS EASTMAN: All right. Did you see the spreadsheets at the time you were preparing your statement?

DR LYONS: Not the spreadsheets, no.

MS EASTMAN: When you signed your statement, is it the case that you didn't have the spreadsheets available to check?

DR LYONS: That's correct.

5 MS EASTMAN: Is there a reason why?

DR LYONS: There was a lot of supporting documentation that was referred to in the statement that I didn't have available at the time I was signing them, no.

10 MS EASTMAN: All right. Do you have any direct and personal knowledge about the content of any of the training courses and training material that you've referred to in this statement?

DR LYONS: I've seen some of the training material when I was at the Agency for Clinical Innovation, because it was being developed over there, but in specifics, no.

15 MS EASTMAN: Okay. Is there any training in the area of access to health for people with intellectual disability that is done at your level within the Department, either at a secretary level or deputy secretary level. Are you required to do any particular training at that level?

DR LYONS: No. I haven't been part of any training, no.

20 MS EASTMAN: Do you have any ongoing training that you have to do around these coalface issues, if that's what the training is? Do you have to do anything around that?

DR LYONS: We would have been participating in different levels of training during our careers within the health system, but I haven't had any of that training in the last three years in this role, no.

25 MS EASTMAN: Now, in the course of your career, have you done any specialised training in relation to health care needs or access to health for people with intellectual disability or, more broadly, cognitive disability?

DR LYONS: Not in recent times, no.

MS EASTMAN: Can I turn to your second statement. And, Commissioners, I'm very conscious of the time, and I will try to complete in the next 10 minutes or so.

30 COMMISSIONER SACKVILLE: I didn't.

MS EASTMAN: Dr Lyons, in your - - -

COMMISSIONER SACKVILLE: I didn't say a word.

MS EASTMAN: No, but I picked up the message. Dr Lyons, I know you are very keen to talk about some of the important initiatives undertaken by New South Wales Health. And your second statement provides a very detailed and comprehensive
5 overview about some of the initiatives taken in relation to Specialised Intellectual Disability Health Teams and the Hubs. I am aware that the Royal Commissioners have read your statement and carefully considered its contents.

10 Can I ask you this. In the time that we have available, in addition to what you have already told us in the course of answering questions about the specialist teams, what would you like to tell us about the way in which the pilot program operated and what that's now meant for the rollout into the three new intellectual disability health teams in Hunter, New England, I think it's Sydney South – is that right – and then western New South Wales. So, rather than me asking questions, here's the opportunity to tell the Royal Commission what you'd like to say in addition to what's in your statement.

15 DR LYONS: Thank you. So those three Hubs that were established first were evaluated. And the evaluation highlighted the fact that they were providing very positive supports for people who were being cared for in our system with intellectual disability, and that they were helping to support the clinicians and clinical teams who provide care in a range of care settings to do – to do things in a better way and be
20 supported to do that. And the feedback from patients, carers and relatives was very positive, as well.

25 So we highlighted the fact, though, that they were only in three spots, that they weren't connected up and they weren't making a difference at the system level; they were actually only operating at the Health District level. And so we were keen to build on the evidence that existed that they were doing good things and enhance them quite significantly. So there was an additional injection of funding to enable three more to be established. But not only that, to create this network of support that enabled that expertise to be available across the whole of the state through connections at the Local Health District level. So - - -

30 MS EASTMAN: So could I – how is that going to work at a practical level?

DR LYONS: Yes.

MS EASTMAN: So some people listening to you talk about that might say, “That sounds like a fantastic new initiative, but what is that going to mean in terms of the delivery of health care on a district-by-district basis?”

35 DR LYONS: Yes. So there's clinical nurse consultant or senior allied health person who's been identified to be appointed in each of the districts that doesn't have one of the Hubs. And each of the Hubs has been connected to make sure that they have a responsibility to provide support to a number of other districts that don't have those Hubs available. So it creates a network and a linking.

What that means is that a person who's cared for in one of the services at a Local Health District that doesn't have that expertise in the district can, through the connection of that clinical nurse consultant, who they will be aware of is there to provide that support, get practical advice, to care, to support care right then. But, in addition to that, can access the specialist team at the other district to get either an outreach service, if it's a particularly complex case or challenge that they're dealing with, or to provide advice through tele-health or over the phone to help them do – or provide the care in a better way that meets the needs of the individual. So the whole idea is to connect up to that expertise and knowledge. But in the process the concept is that we actually raise the capability of all of our clinical teams, because they start to become aware of what they need to do differently by being able to access that knowledge.

MS EASTMAN: So how is that going to be measured? Because we might ask you, and the Chair has just asked you, about The Essentials document. So there's elements of The Essentials document that seem to fit quite neatly with being able to undertake some measurement of whether or not the new programs are going to be successful.

DR LYONS: And they will be - - -

MS EASTMAN: So what's the proposal to do there? It may not be The Essentials, but if it's not The Essentials, what is it?

DR LYONS: So we are very keen to ensure that we do create a method to evaluate the impact, both at the individual level and at the system level. And so we're developing an evaluation program now. These next phase of the Hubs are being implemented as we speak and not fully operational yet. And I would anticipate that the sorts of performance indicators that you've highlighted in a number of the documents that we've talked about today would become the basis on which we would assess impact.

MS EASTMAN: How is that going to be done?

DR LYONS: Well, we'll need to set up a reporting process to enable that information to be captured where it's not captured by existing systems. And that's the challenge I've talked about before around data and ensure that there's a mechanism to report progress periods over time, probably annually for this sort of change.

MS EASTMAN: Is there an expectation that if the evaluation points to some successful indicators in terms of better health outcomes for people with intellectual disability, that New South Wales would look to roll this out through every Local Health District?

DR LYONS: That may well be a challenge. And we actually talked about this in the context of the next phase of investment, is that the people who have these highly specialised skills don't exist in every district, particularly when you get out to the rural and regional districts. So it's about having the personnel, the professionals who
5 are actually employed in this service are available locally who can actually come around and be part of that Hub with that expertise and knowledge. And I think we chose the path we went down at this point in time is because we don't believe we have all of that available everywhere. And it's about how we make those connections.

10 MS EASTMAN: And, in terms of the evaluation, is it the expectation that you will evaluate these initiatives just internally in Health or will you partner with external agencies in relation to the evaluation?

DR LYONS: So that will be something to assess, but we're very open to the fact that, you know, having independent analysis of what we're doing is important, too.
15 It's not just the internal assessment; it's often benefit to have independent assessment. And the other thing is that if we are identifying something which is a value, then how do we communicate that more broadly, not just to the system in Australia but internationally? So often we look at how we might partner with maybe a research organisation, think about what might ultimately be published in the
20 literature around those changes if they're positive.

MS EASTMAN: And, in terms of research organisations, the Royal Commissioners asked some questions last week when Professor Julian Trollor was here about what research organisations exist, either at university level or otherwise, around the country. And I think one issue that came up in relation to Professor Trollor's work at
25 the University of New South Wales was that that had been funded by New South Wales Health, and also another Department for the past 10 years. And, as I understand it, New South Wales Health has made a commitment to fund that role on an ongoing basis; is that right? I just want to clarify some evidence that Dr Trollor gave last week.

30 DR LYONS: Yes. We've made a commitment – we've recommended that that funding be continued, yes.

MS EASTMAN: For the whole of the funding or just the half of the funding?

DR LYONS: The component that we provide.

MS EASTMAN: All right. What about the other component? Where does that
35 leave you? Some might say, "New South Wales is New South Wales. Does it really matter whether it's Health or Family and Community Services, or Ageing and Disability?"

DR LYONS: Well, I'm not aware of the other component at this point in time.

MS EASTMAN: Okay. In terms of other research centres, coming back to the Commonwealth roadmap, element 10 talks about developing centres of excellence. And that's part of the long-term 10-year outlook. Is that something that New South Wales would commit to? And I'm not asking you to do this in the witness box, but in principle commit to in terms of its participation at a national level?

DR LYONS: I think our commitment to supporting Professor Trollor's work is an example of where we are committed to that endeavour. We're very fortunate to have the relationship we have with him and to have been able to support his organisation. It's not just through the funding of the Chair; it's been through a range of different pieces of work we've commissioned him to do over time.

MS EASTMAN: But if his Centre is not – I'm not talking about him personally, but if his Centre is not funded beyond June this year, you're going to lose that – the benefit of that research; is that right?

DR LYONS: Which is why we've made the commitment to continue our component of the funding.

MS EASTMAN: Okay. I'm conscious of the time. And you've been very politely answering questions for a long time now. I just want to raise one final issue with you. And Ms Furness may have some questions, as well. And if this is outside an area of your responsibility, tell me, but I may need you to let the Royal Commission know who we should ask.

One issue that's come up during the course of the evidence is that when a person dies and they die with an intellectual disability, it seems to be customary that the person's intellectual disability is listed on a death certificate as part of a cause of death. Now, it may be the examples that we heard are aberration and one-off situations. But the evidence seems to indicate that this is common. Does New South Wales Health have any role in terms of guidelines or policies in relation to medical practitioners who have to certify a cause of death and the extent to which a person's intellectual disability would customarily be included as a cause of death?

DR LYONS: So I might take it on notice about where to direct the question, because - - -

MS EASTMAN: Thank you.

DR LYONS: - - - certifying death occurs in many situations outside of the organisations that New South Wales Health has responsibility for by practitioners who have no association with New South Wales Health.

MS EASTMAN: All right. Thank you. If you can do that.

DR LYONS: Thank you.

MS EASTMAN: Commissioners, as I said at the beginning, there's a large amount of information in Dr Lyons' two respective statements. And I haven't asked him about everything in those statements. If there's any particular matters that I've overlooked that, Commissioners, you've got questions, we can do this now.

5 Otherwise, Ms Furness may have some questions.

COMMISSIONER SACKVILLE: Thank you. Ms Furness, do you have any questions?

MS FURNESS: No.

10 COMMISSIONER SACKVILLE: No. Thank you. Dr Lyons, thank you very much, both for your detailed statement and for giving evidence today. Thank you very much. And that concludes your evidence.

<THE WITNESS WITHDREW

[12.39 pm]

15 COMMISSIONER SACKVILLE: Ms Eastman, should we now adjourn for lunch or do you have more for us?

MS EASTMAN: I think it may be convenient to adjourn for lunch. This completes the evidence in relation to New South Wales. And then we will turn to the Commonwealth after lunch. But if we could perhaps come back at 1.30.

20 COMMISSIONER SACKVILLE: Yes. We can certainly come back at 1.30. Will that give us enough time – I won't say to dispose of the Commonwealth, but to deal with the Commonwealth?

MS EASTMAN: I'm not going to dispose of the Commonwealth, but it will give ample time. Our witnesses for the Commonwealth – we have three witnesses - - -

25 COMMISSIONER SACKVILLE: Yes.

MS EASTMAN: - - - who are going to give evidence together.

COMMISSIONER SACKVILLE: Together. Right.

30 MS EASTMAN: Rather than consecutively. I can see they're here ready. But I think – I don't think we should have any difficulties making sure that we use the time available today.

COMMISSIONER SACKVILLE: Thank you very much. We'll adjourn to 1.30.

ADJOURNED

[12.40 pm]

RESUMED

[1.37 pm]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

5 MS EASTMAN: Thank you, Commissioners. And I apologise for that short delay in commencing after lunch. Commissioners, you will see that we have a panel of three witnesses speaking to the evidence for the Commonwealth. Perhaps we will deal with their oaths and affirmations.

COMMISSIONER SACKVILLE: Yes, please. You may each take the oath or affirmation as you wish.

10

<SIMON BROOK COTTERELL, AFFIRMED

[1.38 pm]

<ANDREW HARRIS SINGER, AFFIRMED

[1.38 pm]

15

<TANIA RISHNIW, AFFIRMED

[1.38 pm]

COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: All right.

COMMISSIONER SACKVILLE: Ms Eastman will now ask some questions.

20 MS EASTMAN: I might deal with each of you in turn. One second. All right. Can I start with you, Ms Rishniw. Your name is Tania Rishniw?

MS RISHNIW: It is.

MS EASTMAN: And you are the acting Deputy Secretary in Health Systems Policy and Primary Care in the Commonwealth Department of Health?

25

MS RISHNIW: I am.

MS EASTMAN: And you prepared a statement dated the 5th of February 2020?

MS RISHNIW: I did.

MS EASTMAN: And there's an addendum that you want to make to the statement. So what – which paragraph and what would you like to add?

MS RISHNIW: Thank you. In the last sentence of paragraph 71 of my statement, I would like to change it to be expressed as:

Subject to the matters set out in paragraph 76(b) and 78(a) of the statement.

So that it reads as follows - - -

5 MS EASTMAN: Just – and I will just ask you to slow down a little bit.

MS RISHNIW: Sorry:

I am not aware of the Department funding any additional programs that specifically target people with cognitive disability who live in rural and/or remote communities, save for those outlined in paragraphs 76(b) and 78(a) below.

10

MS EASTMAN: So with that addendum, are the contents of the statement true and correct to the best of your knowledge and belief?

MS RISHNIW: Yes.

15 MS EASTMAN: So, Commissioners, you will find a copy of that statement in tender bundle part C, behind tab 4. And that will be exhibit 4.29, if I can deal with the tender of that now.

COMMISSIONER SACKVILLE: Thank you.

20 **EXHIBIT #4.29 STATEMENT OF TANIA RISHNIW DATED 05/02/2020
(STAT.0038.0001.0001)**

MS EASTMAN: Next, Dr Singer. So you are Andrew Harris Singer?

DR SINGER: That's correct.

25 MS EASTMAN: And you have also prepared a statement for the Royal Commission.

DR SINGER: Yes.

MS EASTMAN: And have you got a copy of your statement with you?

DR SINGER: Yes, I do.

MS EASTMAN: It's made on the 5th of February.

DR SINGER: That's correct.

MS EASTMAN: And the contents are true and correct to the best of your knowledge and belief?

DR SINGER: Yes, that's true.

5 MS EASTMAN: And I think I omitted you're presently the Principal Medical Adviser to the Chief Medical Officer in the Department of Health.

DR SINGER: That's correct.

10 MS EASTMAN: All right. Commissioners, a copy of Dr Singer's statement can be found in tender bundle part C, tab 5. And if I tender that now, that will be exhibit 4.30.

COMMISSIONER SACKVILLE: Yes.

EXHIBIT #4.30 STATEMENT OF DR ANDREW SINGER DATED 05/02/2020 (STAT.0039.0001.0001)

15

MS EASTMAN: And, Mr Cotterell, your name is Simon Brook Cotterell?

MR COTTERELL: That's right.

MS EASTMAN: And you are the First Assistant Secretary in the Primary Care Division of the Commonwealth Department of Health?

20 MR COTTERELL: I am.

MS EASTMAN: And you've made a statement dated 5 February this year?

MR COTTERELL: I have.

MS EASTMAN: And are the contents of that statement true and correct?

MR COTTERELL: Yes.

25 MS EASTMAN: Commissioners, a copy of Mr Cotterell's statement is found in tender bundle part C, behind tab 6. And if I can tender that document now and it will be exhibit 4.31.

COMMISSIONER SACKVILLE: Thank you.

**EXHIBIT #4.31 STATEMENT OF SIMON BROOK COTTERELL DATED
05/02/2020 (STAT.0040.0001.0001)**

5 MS EASTMAN: All right. The way in which I think we're going to deal with the
evidence today is that I will refer to particular paragraphs of the witness statements
where issues have been addressed, but it's likely that some of the issues that I will
raise in the questions this afternoon might touch upon all three witness statements.
So I have invited our witnesses to make their comments as they consider appropriate.
And I will try to do this in an orderly way. So I might just ask, for example, you, Mr
10 Cotterell, about aspects of your statement, but then I may not go to the specific
paragraphs in Dr Singer's or Ms Rishniw's statement. Does that – and if you get
confused, let me know. I'm probably confused too but we will work it out. All right.
I want – I want to start by asking all of you – and it may be you, primarily, Ms
15 Rishniw, about the Department of Health at a Commonwealth level. So within the
Department of Health, it's a very large organisation; is that right?

MS RISHNIW: It is.

MS EASTMAN: And there's a Secretary to the department.

MS RISHNIW: There is.

20 MS EASTMAN: And then under the Secretary there are a number of divisions or
particular subject matter areas; is that right?

MS RISHNIW: There are a group of Deputy Secretaries who report directly to the
Secretary. We refer to them as "groups" and, under those groups, there are a number
of divisions.

25 MS EASTMAN: And the group that you head up is the Health Systems Policy and
Primary Care. So you are acting Deputy Secretary of that area.

MS RISHNIW: That's right.

MS EASTMAN: And Mr Cotterell, you're part of that group; is that right?

MR COTTERELL: That's correct.

30 MS EASTMAN: And, Dr Singer, are you part of the group that is headed up by the
Chief Medical Officer, Professor Murphy?

DR SINGER: Yes. Though the – the structure has changed a little bit in response to
the novel coronavirus, so - - -

MS EASTMAN: Maybe that has elevated right up to a Secretarial level, is it?

DR SINGER: Sure. So – so my home division, which is the Health Workforce Division is – is now under a different deputy secretary.

MS EASTMAN: All right. And is it right, in understanding that current arrangements within the Department of Health, that one of the areas includes an
5 Aged Care Royal Commission Taskforce?

MS RISHNIW: It does.

MS EASTMAN: And that was established to deal specifically with the Aged Care Royal Commission; is that right?

MS RISHNIW: That's right.

10 MS EASTMAN: Has there been any taskforce developed in relation to this Royal Commission?

MS RISHNIW: There has.

MS EASTMAN: And is that part of the Department of Health?

MS RISHNIW: It is.

15 MS EASTMAN: And where would we find that group or aspect of the department? Where does that fit in?

MS RISHNIW: So there's a taskforce within my group in the Portfolio Strategies Division that's specifically dealing with evidence for the Department of Health, and there's a broader organisation through the Attorney-General's Department in
20 addressing the various matters across the Commonwealth.

MS EASTMAN: All right. And if I step back out of the Royal Commission and look at the structure for the Commonwealth Department of Health, is there either a designated position or a person in the Commonwealth Department of Health who has exclusive and specific responsibility for people with intellectual disability and their
25 access to health care?

MS RISHNIW: Not an exclusive position.

MS EASTMAN: All right. And when you say "not exclusive", how does the department then divide up or address responsibilities for people with intellectual disability, or, more broadly, cognitive disability within the current departmental
30 structure?

MS RISHNIW: So the departmental structure tries to cover off on elements of the health system. Within the health system there are various interactions, obviously, for people with a cognitive disability and an intellectual disability. So, for example,

within primary care, as Mr Cotterell will outline later, there has been some work to do with primary care and how do we make that better and more accessible. Within the Workforce Division, looking at how does the workforce deal with issues for people with cognitive disabilities, in the Health Financing Group with how the
5 Medical Benefits Division and the Pharmaceutical Benefits Scheme address those issues. So there's an overarching responsibility, depending on where the interaction's happening.

MS EASTMAN: Has there ever been any consideration of having a central or a very specific focal point for health policy in relation to people with cognitive
10 disability?

MS RISHNIW: Not to my knowledge.

MS EASTMAN: All right. Mr Cotterell, your responsibilities, as the first assistant secretary of the Primary Care Division – and you've only been in this role for about six or so months; is that right?

15 MR COTTERELL: That's right. I think it's eight months by now.

MS EASTMAN: Eight months. Okay. You're responsible for policy and programs relating to, amongst other things, primary health care and the Minister's health primary care 10-year plan. And the National Roadmap for Improving the Health of Australians with Intellectual Disability, primary health networks, dental benefits and
20 palliative care.

MR COTTERELL: That's correct.

MS EASTMAN: All right. So it's a very large portfolio area; is that right?

MR COTTERELL: It's – it's fairly typical of the – the size of responsibilities for officials at my level.

25 MS EASTMAN: All right. And one of the pieces of work that you've been involved in in the last few months is the development of a new 10-year plan; is that right?

MR COTTERELL: That's correct. The - - -

MS EASTMAN: What does that involve?

30 MR COTTERELL: Okay. So the – the Minister's 10-year primary health care plan is currently under development. The Minister announced in early – earlier in – earlier in - - -

MS RISHNIW: 2019.

MR COTTERELL: - - - 2019 that he would be commissioning the Department to develop a 10-year primary health care plan. He initially tasked the Department to develop that by the middle of 2020. We're currently on track to complete it by September of 2020. We're doing extensive consultation to develop that plan. That
5 includes a small steering group – and when I say “small”, it's under 20 people – to steer the department in that work. A larger consultation group involving 90 or more stakeholder organisations, a public discussion paper process and a series of targeted consultations on various issues in the health system or access issues for population groups.

10 MS EASTMAN: All right. So just pausing there, are we right in understanding that, at a very high overarching level, we're talking about a 10-year plan for primary health care in all areas of health; is that right?

MR COTTERELL: That's right. And also picking up the interactions with other parts of the health system and other parts of broader social support systems. So I
15 would expect that would – it would be looking at interactions with the aged care system, interactions with the National Disability Insurance Scheme and other disability supports, interactions with mental health services and with drug and alcohol treatment services, with public hospitals, with private health insurance arrangements and specialist arrangements. So primary health care is seen, I hope, in
20 the health system as the integrating piece, and we're developing the 10-year plan with that in mind.

MS EASTMAN: All right. Ms Rishniw, you refer to this initiative also in your statement. Is there anything you want to add?

MS RISHNIW: No. I think Mr Cotterell has covered it comprehensively.

25 MS EASTMAN: All right. Now, underneath that overarching plan is the work being done in relation to a national roadmap for improving health of Australians with intellectual disability; is that right?

MR COTTERELL: That's broadly right. So the National Roadmap also has a life of its own, and was not restricted to primary health care. So could potentially pick
30 up all of the public hospitals or – or broader areas.

MS EASTMAN: But are these two initiatives which both have a 10-year focus intended to work together, or is it that the National Roadmap in relation to improving the health of people with intellectual disabilities really a subset of a much broader piece of work done?

35 MR COTTERELL: They're intended to work together.

MS EASTMAN: All right. Can I ask you now about the work done with the National Roadmap to Improve the Health of Australians with Intellectual Disability. You deal with this in your statement at paragraph 13. And you make mention of a

roundtable that occurred in August last year. And you say in your statement that the roundtable – second roundtable will occur on 7 April this year.

MR COTTERELL: That's correct.

5 MS EASTMAN: Okay. So what I want to ask you about is the available information that we have for the work that was done on 2 August and immediately following. And have you got a copy with you of the roadmap with the summary recommendations and key elements that was published, as I understand it, shortly after the 2 August 2019 meeting? Have you got a copy of that?

MR COTTERELL: Yes, I do. It's the first exhibit to my statement.

10 MS EASTMAN: All right. And, Commissioners, a copy of this can also be found in part D of the tender bundle behind tab 28. We've got a few copies, if anybody else requires a copy. Yes.

MS RISHNIW: Yes, please.

MS EASTMAN: Mr Cotterell, did you have a hand in preparing this document?

15 MR COTTERELL: Yes, I did.

MS EASTMAN: And would it be fair to say – and please tell me if I've misread anything – that what you seek to do is to summarise what occurred at the roundtable where there are a number of presentations delivered; was that right?

MR COTTERELL: That's right. I – the – at the roundtable, we heard from people with disability, from a carer of a person with disability, from a number of experts, and from some of the primary health networks. And we had a broad-ranging discussion about what the elements of a National Roadmap might include. During that discussion it became clear that we were not going to conclude the work on that day. And it also became clear that we didn't have all of the necessary parties in the room to fully flesh out that roadmap. So - - -

25 MS EASTMAN: All right. So you're aware, aren't you, that a number of people who participated at that first roundtable had given evidence in the proceedings of this public hearing of the Royal Commission?

MR COTTERELL: Yes, I am.

30 MS EASTMAN: And have you and any members of the panel followed the proceedings in the Royal Commission over the course of the last week or so?

MR COTTERELL: I've been reading daily summaries that have been prepared by the Attorney-General's Department.

MS EASTMAN: Have you watched any of the proceedings or read any of the transcript?

MS RISHNIW: So I have watched some of the proceedings and have read daily summaries of the transcripts.

5 DR SINGER: And I'm the same.

MS EASTMAN: All right. And those summaries have been prepared by the respective legal team; is that right?

MS RISHNIW: It's by the Attorney-General's Department.

10 MS EASTMAN: Okay. And those summaries have given you a sense of an overview, what, of the evidence that's been presented or issues arising; is that right?

MS RISHNIW: A daily summary of the evidence presented, the witnesses appearing before the Royal Commission, key themes emerging, and particularly where there's intersections with the health system.

15 MS EASTMAN: All right. And so you're all aware, aren't you, that the witnesses who participated in the Roundtable have also given evidence or touched upon issues that concern the Roadmap and the future policy initiatives, if any, that might evolve from that.

MR COTTERELL: Yes.

MS EASTMAN: So you're all aware of that?

20 MS RISHNIW: Yes.

MS EASTMAN: Okay. When we have asked witnesses about the National Roadmap and its importance, there seems to be a sense that this might be an opportunity for a turning point in the development of a national policy to respond to the health needs of people with intellectual disability in Australia. And there seems to be some optimism, but also, perhaps, some reservation that the information that we've known for a long time, and all of the research that's available that identifies some very significant disparity in health outcomes for people with intellectual disability compared to the rest of the population, that there might finally be an opportunity to address that. Is that the expectation within the Commonwealth Department of Health, that this is an opportunity, and it may, indeed, be a turning point, to address and remedy some of the issues that have been known for a very long time?

30 MR COTTERELL: Yes. Yes. We do very much view it as an opportunity. At the commencement of the Roundtable in August, the Minister sent – Mr Hunt sent a video message to the Roundtable and commissioned the development of the National
35

Roadmap. And he acknowledged the health inequities faced by people with intellectual disability.

5 MS EASTMAN: All right. And what was it that was the cause of the Commonwealth to say, “This is time for the Commonwealth to act”, rather than to look around and say, “Well, the states are doing a reasonable job or not”? Was there some impetus for the Commonwealth to make this initiative in August last year?

MR COTTERELL: As I understand it, in February or March of 2019 the Council for Intellectual Disability met with Minister Hunt. And he, coming out of that meeting, made a commitment to convene a roundtable.

10 MS EASTMAN: Okay. Just looking at the Roundtable document, there’s some recommendations that appear on page 5. So that’s 1 through to 9. And then there’s a discussion about next steps on the following page, page 6. But what I want to ask you about is the key elements of the National Roadmap that appear in appendix B starting at page 9. So can I draw your attention to those matters. Now, the first thing
15 I want to ask you is about the approach to defining intellectual disability. So if I assume that the updates that you have received have informed you that the Commission is taking an approach in this hearing of looking at cognitive disability, of which intellectual disability is one feature, the focus of this roadmap is only intellectual disability; is that right?

20 MR COTTERELL: Correct.

MS EASTMAN: So where would that leave the other cohort of people with cognitive disability, in particular, people who have autism?

MR COTTERELL: I think if there were a desire for people with cognitive disability who don’t fit the definition of intellectual disability to be picked up in the Roadmap,
25 I think that would be something that could be considered by the Minister.

MS EASTMAN: But I think we’ve heard evidence that, while cognitive disability is a helpful term, there are particular needs and interests of people with intellectual disability that may be very different from the cohort of people with autism, or a cohort of people with acquired brain injury, or a broader cohort of people with dementia. So assume, broadly, those are the areas that we have addressed by way of
30 cognitive disability. What – when I look at this document in defining intellectual disability, it seems to just be at that narrower focus. Is there a risk that if you automatically assume that autism would fit into this model, that that would change these elements or cause you to reassess the appropriateness of this type of policy
35 framework?

MR COTTERELL: So if I could respond to two elements of that. In relation to people with dementia, as part of the primary health care 10-year plan, we are proposing a separate roundtable process on dementia. In relation to the needs of

people with autism, my instinct is that – that there would need to be a different focus, and that would add significantly to the scope of work needed to finalise the roadmap.

MS EASTMAN: Could that be done as a separate stream, in the same way that you've developed a National Roadmap for Improving Health of People with Intellectual Disability, to have a parallel stream that mirrors the process and the steps for people with autism?

MR COTTERELL: I think it could. It would take some resourcing. And I think the Minister would need to consider that.

MS EASTMAN: But has any consideration been given to how you deal with autism in the context of the work and the preparation for the Roadmap dealing with the interests of people with intellectual disability?

MR COTTERELL: Until you raised it with me right now, no.

MS EASTMAN: Okay. Well, let's come back and focus on intellectual disability - - -

COMMISSIONER SACKVILLE: What will it need? Will it need the equivalent of Mr Simpson to get to the Minister on behalf of people with autism?

MR COTTERELL: So I think the question just now would cause me, after this hearing, to raise the issue with the Minister.

COMMISSIONER SACKVILLE: Very good.

COMMISSIONER ATKINSON: I must say, Mr Cotterell, I appreciate that you're actually answering the questions. It's very refreshing.

COMMISSIONER SACKVILLE: So far.

MS EASTMAN: I don't want people to have a sense of trepidation.

COMMISSIONER SACKVILLE: How many states were invited to the roundtable in August 2019?

MR COTTERELL: No states were invited to the this roundtable.

COMMISSIONER SACKVILLE: No. Was there some reason for that? I thought it might have been the invitation to New South Wales had got lost in the mail, but apparently nobody got invited.

MR COTTERELL: The process of developing the list of invitees was one that took place between my current staff and the Council for Intellectual Disability. As I understand it, this was always seen as a first step. And maybe some of the

5 trepidation of the sector that's been expressed about hope that this will make a difference, versus, you know, some understanding that this had been an issue for a long time and not much seems to have happened. I think the intention was to keep it small. But, as I said earlier, the discussion on the day made it very clear that we would need the states in the room and we agreed to invite them to the next roundtable.

COMMISSIONER SACKVILLE: So they will be coming in April?

MR COTTERELL: Yes. All of the States and Territories have been invited in April.

10 COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: In your statement, Mr Cotterell, you say that the outline of the roadmap identifies elements in the short term. That's one to two years; medium term, three to five; and long term, six to 10 years. And you say in your statement at paragraph 16:

15 *Decisions about funding for and commitment to elements of the roadmap are future decisions for the Commonwealth, state and territory governments and the non-government stakeholders.*

So that's paragraph 16. So at the time you prepared your statement, are we right in understanding that no decision had been made about any funding of any kind in relation to the elements in the roadmap?

20 MR COTTERELL: Correct.

MS EASTMAN: And that position's changed, hasn't it, as of today?

MR COTTERELL: Yes. The position changed a few days ago when the Minister made a decision to allocate funding to support the – what's referred to in my evidence as the Primary Care Enhancement Program. And the Minister this morning announced \$6.5 million to support that.

MS EASTMAN: So there was a press release this morning that announced a 6.5 million investment into the Primary Care Enhancement Program. And how does that fit in, or how is that relevant to any of the elements, be they short, medium or long term, in the roadmap? Because I assume you were unaware of that when you prepared your statement.

30 MR COTTERELL: That's correct.

COMMISSIONER SACKVILLE: It is 6.5 million over four years?

MR COTTERELL: That's correct.

COMMISSIONER SACKVILLE: Yes. So it's 1.75 million per year. Is my maths correct? More or less.

MR COTTERELL: I think there is more money early on to develop the national resources.

5 MS EASTMAN: All right. I want to, now, turn to the elements and the timeframes. And no doubt you've been told in your update that a number of witnesses have been asked questions about why a 10-year timeframe and how decisions have been made thus far about what is short term, what is medium term, and what is long term. So can I come back to page 9, which is in appendix B of the Roadmap. And these are
10 the various elements. And I don't want to spend a huge amount of time on this, but I do want to have an understanding about how certain elements have been allocated either as short or long term, and the rationale for that. So that's the focus of the questions. So with the model of care, which is item number 1, this is looking at better models of care that may be needed to – for children, youths, adults with
15 intellectual disability, that:

...better equipped the health system to meet the needs of people with intellectual disability across their lifespan –

etcetera. So that's said to be a short-term objective to be achieved in one to two years. Looking at that, though, that just seems to be, almost, the core of what you
20 wish to achieve. What is the – at this stage, what is the intention in terms of what the community is likely to see by way of implementation in two years' time, assuming that you keep to a one to two year timeframe?

MR COTTERELL: So if I can address your general question. So, at the first roundtable, we had one day to develop the work. We tried to get through as much of
25 the work as we could, and it was very clear that we hadn't developed a full roadmap on that day. We tried to, with everyone in the room, agree on the elements and have an initial discussion about how quickly they could be implemented, but we didn't complete that discussion. So, after the roundtable, my staff had further discussions with the Council for Intellectual Disability and turned the document into the form
30 that it is now. But I would emphasise that that form is still a draft and there would have been some – some decisions about what was allocated as short, medium and long term that were based on instinct or the best guess at the time. So I – I think the models of care one that you pointed out probably related to the urgency of that issue that we heard in the room, but, actually, all we heard in the room that day was that
35 needed to be urgently addressed. We didn't hear any proposed answers to it. And if I could – and I have been reading the summaries of the evidence, and I think the most concern that has been expressed has been about on page 11, element 10.

MS EASTMAN: Yes. Well, I did ask the questions, I think, of Professor Lennox earlier in the week in terms of centres of excellence and why would it take 10 years.
40 And you may have seen that reported back. Well, I will ask you: why would it take 10 years to develop a network of centres of excellence in circumstances where we do

know from the evidence that there are already centres of excellence but some precarious funding in relation to them?

MR COTTERELL: Okay. So the long-term elements are allocated to the six to 10 year period. This is one of those ones that we approached with some trepidation.

5 MS EASTMAN: Why is that?

MR COTTERELL: Because the – because the centres of excellence are funded, currently, by the States and only some of the States fund centres of excellence, and the States were not in the room on that day. So – so when we have the States in the room we will be having a discussion about – with them about how realistic this

10 proposal is and how quickly it could be approached.

MS EASTMAN: Does that mean that, on element 10, that if element 10 was to be achievable, that is going to require some contribution of the States and Territories in terms of funding?

MR COTTERELL: Not necessarily. Our starting position would be that, given the States and Territories currently fund these centres, that they should continue to do so and develop them. But, as I said, some of them don't have those centres, and we would need to have a discussion about whether that's a realistic option. The Commonwealth might also need to decide how involved it needs to get in them. But that – I think that would take some iteration.

15 MS EASTMAN: All right. I think the Chair may – sorry.

COMMISSIONER SACKVILLE: Who funds those centres of excellence at universities in areas other than health?

MR COTTERELL: So I'm aware of one Centre of Excellence in relation to the health of people with disability at the University of Melbourne - - -

25 COMMISSIONER SACKVILLE: I meant other than health. Generally, are there not centres of excellence at universities across a range of areas?

MR COTTERELL: I think – I think there are and I think they have a range of funding sources.

COMMISSIONER SACKVILLE: The Commonwealth funds some of them, doesn't it?

30 MR COTTERELL: That's right. Some through the National Health and Medical Research Council in the area of health.

COMMISSIONER SACKVILLE: So why is it so important to have the States contribute to centres of excellence in the health? Is that just because they always have? Or this is part of the great Australian tradition of cost-shifting?

5 MR COTTERELL: I think this is – I think this is – these centres of excellence are clinical centres of excellence, and so they're not pure centres – centres of excellence that might – purely academic ones that might be in existence through other funding sources.

COMMISSIONER SACKVILLE: What's the distinction between a pure centre of excellence and an impure one?

10 MR COTTERELL: Well, a purely academic one wouldn't have some clinical services attached to it. That's – that's my understanding. I don't think that's some general terminology.

COMMISSIONER SACKVILLE: That's what - - -

MR COTTERELL: I'm just trying to understand my understanding.

15 COMMISSIONER SACKVILLE: And faculties of medicine do have clinical activities; do they not? So do schools of psychology; do they not?

MS RISHNIW: They do, Commissioner. I think our point is we wouldn't want to duplicate already existing infrastructure and expertise that has been developed and funded by the States in these centres of excellence. We would need to review where
20 the focus is and how that fits, obviously, with the Roadmap. We would need government to make decisions about funding and allocation. And I think we, certainly – I've had an opportunity to hear evidence about – concerns about making sure we've got integration nationally. So, once again, we wouldn't be recommending that the Commonwealth fund its own centres of excellence if
25 something that is successful and that is robust is already in existence.

MS EASTMAN: Can I – can I ask you about a few of the other elements. And just coming back to the beginning, I think we've touched on models of care. But a second element that's identified as short term is better use of the existing MBS items. And this is a matter, I think, that each of you may have touched on in your
30 statements. So you're saying:

Promoting, supporting and monitoring greater uptake and use of annual health assessment and other existing MBS items will be critical to improving preventative health care and health outcomes for people with intellectual disability.

35 So while we're looking at the Roadmap, but given that this is a – an issue that's well-known to the Commonwealth Department, isn't it?

MS RISHNIW: In terms of well-known to the department, certainly, the particular MBS items that I think all of us have referred to in our statements that go to assessments, length of time of assessments, and the detail of those MBS items, they've been in existence, I understand, from 2008. At the Commonwealth level, we have availability and access to data that shows use of those items, but not to the detail of how they're used and the – whether they're used for people with an intellectual disability within that aggregate figure.

MS EASTMAN: So we have heard evidence that the – there were some specific items introduced in 2006. And the evidence was there have been 8000 uptake in, say, the last year, and that had to be looked at in the context that there are almost half a million people in Australia with intellectual disability. So Dr Lennox talked about this and so did Mr Simpson in their evidence. And I know that you weren't here and didn't hear it directly. I think what we were interested in – and Mr Cotterell, you deal with this in paragraph 17 and, Ms Rishniw, you deal with it in paragraph 42 and, Dr Singer, you deal with this partly in paragraph 24 of your statement. And, Dr Singer, I think you've provided some documents relevant to the Medicare Benefits Schedule numbers. So I think we were interested in understanding, from the comments made in each of your respective statements, is how does this actually work? And if the uptake is so low, what is the reason for that? And I will open it up to whoever on the panel wants to address that?

DR SINGER: So I will – I will start, Ms Eastman. So the – the Medicare Benefits Schedule is essentially designed to provide a description of services that can be provided, and a mechanism to pay for those generally through a patient rebate, though, of course, providers have the ability to – to bulk bill if they so wish.

As a result, usually these items are – are created in response to an identified need, either by providers or groups advocating for a particular area that needs to be covered. Certainly, these items were created in consultation with both the – the National Council for Intellectual Disability and the New South Wales Council for Intellectual Disability and the Royal Australian College of General Practitioners. Generally, once the item is created, the Department informs the profession that those items are available, but, as a rule, we don't promote use, so to speak. That's not - - -

MS EASTMAN: Well, just pausing there, do you think – do you think, though, in the context of the idea of annual health assessments and longer consultation times for people with intellectual disability, that this is something that does require some promotion among the profession?

DR SINGER: Well, certainly the – my understanding of the evidence that's been presented is that that may be the case. Yes.

MR COTTERELL: Can – could I add to that? So the reason that it's on the action plan – sorry, the Roadmap, is so that we do do something that's different than what is done in a standard way under the MBS. So - - -

MS EASTMAN: And is that something that's going to be developed in April and beyond?

MR COTTERELL: Yes, I hope so.

5 MS EASTMAN: And if you have a short-term focus, which is one to two years, if the Royal Commission came back and asked you about what the progress was in a year's time, what is your expectation of any change within the course of the next 12 months?

10 MR COTTERELL: I expect we would have gone to our government with a proposal, and if – if they agree with that and there's funding to support it, that it would have rolled out before then.

MS EASTMAN: Right. And what sort of funding do you think we're looking at for being able to remedy better use of the existing Medicare Benefit Schedule items?

MR COTTERELL: I – I could only speculate.

15 MS EASTMAN: All right. So somebody would need to do some economic modelling; is that right?

MR COTTERELL: I don't think it's economic modelling. It's costing of the communication activity.

MS EASTMAN: Okay.

20 MR COTTERELL: And we would have to have a discussion about what the most appropriate form of that would be to raise the appropriate awareness of the items.

MS EASTMAN: All right.

COMMISSIONER ATKINSON: But that's what you're looking at.

MR COTTERELL: That - - -

25 COMMISSIONER ATKINSON: Some sort of campaign to raise awareness of the items which would need to be funded. And you would expect that that would cause an uptake in that item?

30 MR COTTERELL: We – we would hope so. I think there are a whole lot of other issues that you've been discussing that might contribute to the low uptake as well. So I think that people who are not comfortable to see people with intellectual disability are not comfortable to see people with intellectual disability. I think that's – there's an underlying issue here.

COMMISSIONER ATKINSON: And does the Commonwealth have a role in changing the level of discomfort that health practitioners might feel in treating people with intellectual disability?

5 MR COTTERELL: Yes. And – and that’s part of the intention of the Primary Care Enhancement Program that I spoke about before. We need to skill up general practitioners and – and others in the health system to better help meet the needs of people with intellectual disability.

COMMISSIONER ATKINSON: So during the course of this Commission, you will be assessing how well your initiatives are working in that area?

10 MR COTTERELL: That’s right. So the – so we will be having an evaluation strategy for the Primary Care Enhancement Program, and I would also expect, at the second roundtable, we would have a discussion about overall evaluation of the whole Roadmap. And – and hopefully putting in place mechanisms to make sure that we implement it. So – and by that I mean having some external check on us in the form of a group – an external group – to make sure that we’re implementing the Roadmap.

15 COMMISSIONER SACKVILLE: Presumably, any analysis of the costs of a promotional program would need to take into account countervailing savings, because, presumably, some of the services that would be capable of being rendered under the – for people with intellectual disabilities specifically, might be billed under different schedule numbers at the moment.

20 MR COTTERELL: Go ahead, Andrew.

DR SINGER: Yes. I think that would be correct, Commissioner. Certainly, within General Practice, you could argue this is an opportunity cost, that the time that you spend seeing one person with a problem could be used in a different and potentially better way. So, yes, I agree that better use of these items may lead to less use of other items.

MS EASTMAN: Commissioner Galbally.

30 COMMISSIONER GALBALLY: Yes, I just wanted to come back to the assessment. And we heard yesterday that, with regard to group homes, there might have been an inclination to tick a box and to put “not appropriate” or “doesn’t apply” against really vital issues like women’s health care. So, you know, a real sort of look at how that could be overcome needs to be added to the roundtable actions, perhaps. I – you know, I wondered what you – you know, whether that had already been done, whether that has been taken into account?

35 MR COTTERELL: Commissioner, I – that – I thought that was very powerful evidence, and that gave us a good place to look at the interaction between the health system and the disability system. So those sorts of examples are incredibly useful for the – for the department to try to address those issues that are not working. I would

also add that those sort of preventative health approaches, there's – there are a number of strategies and plans being developed right now. One of them is the National Preventative Health Strategy, and I am working with colleagues who are preparing that strategy, to make sure that my primary health care 10-year plan and that strategy collect up all the necessary issues between them.

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COMMISSIONER GALBALLY: And people with disabilities are in that plan and people with intellectual disabilities?

MR COTTERELL: That's correct.

COMMISSIONER BENNETT: Could I also - - -

10 COMMISSIONER ATKINSON: Fortunately, the Royal Commission is going for long enough that you will be able to come back and tell us whether or not - - -

MR COTTERELL: I look forward to it.

COMMISSIONER ATKINSON: - - - your strategies are working.

MS EASTMAN: Commissioner Bennett.

15 COMMISSIONER BENNETT: I just want to draw on the point about there being other information and other work over decades that has been done in this area, and yet we've reached this point where we suddenly think it's a burning platform on the Roadmap. The national – I think it's – I'm trying to work out whose evidence it is – but there's the Australian Commission on Safety and Quality in Health Care and it, from what I'm reading here, is that there is special standards – specific items for the clinical care and standards for caring for people with cognitive impairments.

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Some of the points raised include making changes like support person, diagnostic overshadowing, which we've heard about. Can you, firstly, explain how does that sit in the future work that you're doing? Secondly, there was a campaign that you ran for two years that was conducted, it was supposed to go to hospitals and other medical practitioners to help them improve the care and quality of care for patients with cognitive impairment. How do we know how that has progressed? What have been the measures? And what are the consequences of those hospitals and practitioners not complying to those standards?

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30 MS RISHNIW: So, Commissioner, I think you're referring to my evidence that mentions some of the quality and safeguarding mechanisms across the Commonwealth. And I will try and answer your questions to the my best ability, but implementation of those standards are for the Australian Commission on Safety and Quality in Health Care, which is a separate statutory agency within the health portfolio. That Agency is responsible for setting the national standards for safety and quality, particularly in private and public hospitals and public dental services. So it

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specifically sets the standards that all hospitals are required to meet in terms of patient care.

5 Within those standards – and there are eight, from memory, standards – they specifically developed an element that dealt with safety and quality standards of caring for people with cognitive impairment and built those into the quality and safety standards particularly in terms of partnering with consumers and comprehensive care standards referenced people with cognitive impairment, in particular. Those standards all hospitals are required to meet. The Safety and Quality Commission accredits agencies in the States and Territories to assess
10 compliance with those standards. And if a hospital does not comply with those standards, action is taken by the Safety and Quality Commission on Health Care. That can vary from providing 90 days to remedy, depending on the severity of non-compliance with those standards. It can include working with that hospital to make sure that they meet those standards, or it can include notifying the State Government, who is the administrator of the hospital that action needs to be taken or the hospital risks losing accreditation. Compliance with those standards is assessed by
15 accrediting agencies at the state and Commonwealth – at the state level. And those accrediting agencies are accredited by the Safety and Quality Commission on Health Care. They are audited every three years to ensure compliance with those standards.
20 COMMISSIONER BENNETT: Is it your assessment that they are complied with in both the spirit and the format in which they're presented?

MS RISHNIW: I wouldn't want to comment in detail on whether all of them are complied with, but certainly public hospitals and state and territory governments treat those standards with great respect. And they know that the consequences of not meeting those standards can risk accreditation of those hospitals and can risk public
25 safety. So they are taken very seriously.

COMMISSIONER BENNETT: And what data – do you have data where hospitals have been assessed that they've not met the standards in relation to those that are specific for treating patients with cognitive impairment? Which hospitals, how often,
30 and what the remedial action they took?

MS RISHNIW: So I don't have that data, Commissioner. I'm happy to take that on and request that from the Australian Safety and Quality Commission on Health Care.

COMMISSIONER BENNETT: Thank you.

MS EASTMAN: Can I come back to the roadmap. And I wanted to just finish on
35 the items that are identified as short-term initiatives and then come to the medium term and back to some of the longer term. So dealing still with the short term, in element number 5, a short term initiative may be better coordination with other sectors. And this includes making the NDIS systems more accessible for users to navigate. And there's a reference there to:

Enabling and supporting better linkages between health care and NDIS providers.

Now, Royal Commission has heard from a number of witnesses about the importance of integrating health with other areas, including disability services. Is this what
5 element 5 is directed to or is it something a little narrower?

MR COTTERELL: No. That's what it's directed to.

MS EASTMAN: And what – if this is a short-term initiative, what could the community expect to see – and this might be your expectation – in a short term about how the NDIS system could be more accessible for users to navigate?

10 MR COTTERELL: So the – I think that question, in relation to navigating the NDIS in relation to Health's responsibilities there, I would expect that the Primary Care Enhancement Program would also include some element of that for general practitioners. So improving the capacity of primary health networks, to supporting
15 general practitioners to connect people up in the right way in the National Disability Insurance Scheme system.

MS EASTMAN: That's going to be somewhat ambitious, isn't it, to achieve in one to two years if we look to the primary care network or primary health networks to achieve that?

20 MR COTTERELL: Yes. And if I go back to my earlier answer, some of these timings are probably not right. They were done as part of a draft and we need to discuss them further at the roundtable. Could I also add that the National Disability Insurance Agency was present at the first Roundtable and we need to have more discussions with them about how to make some of this work.

MS EASTMAN: And another short-term initiative identified as element 6, support
25 for people with intellectual disability and their families. And this has been very much the focus of the evidence of the Royal Commission in the previous week or so. We've heard from many families about their experience trying to navigate. And there seems to be a broad consensus that it needs to improve; is that right?

30 MR COTTERELL: That was a very strong message that we heard at the roundtable. If I go to the timing, it's the same issue as the previous item. This is an issue that was identified as urgent for addressing. We will be trying to work through the roundtables to make that happen, but it may be that one to two years is not the realistic timeframe.

MS EASTMAN: And then the final short-term initiative is – we've touched on this
35 – which is the Primary Care Enhancement Program. That's element 8. And this is the announcement for the funding today; is that right?

MR COTTERELL: Correct.

MS EASTMAN: And just looking at this element, this is going to build on existing infrastructure and focus on the needs of people with intellectual disability with a number of components. One is training and support for the Primary Health Network lead site. So I understand there's going to be four – a number of lead sites. Four
5 lead sites to pilot this over a four-year process; is that right? It's going to take one or two years to then set up the four-year program?

MR COTTERELL: So the – so at the roundtable we specifically tried to avoid the use of the word “pilot”, because it implies that you might pilot the program and then not continue it. So there was a determination to set up a continuing program of work
10 here. In relation to the four-year program, in the first year I would expect that the Primary Health Networks would be working up their capability and that the national resources would be developed and then in the remaining three years they would be tested and rolled out.

MS EASTMAN: All right. Can I ask you now about the medium term? And two
15 significant elements, element 7 and element 9, seem to focus on curriculum development and training. And these are both identified as medium-term objectives. And the Royal Commission has heard evidence about either lack of training, inadequacy of training, and very much heard over the course of the past two weeks the need for training. And we have received from some of the colleges copies of
20 their curriculum and an explanation about training. And, Dr Singer, I'm looking at you, because you have addressed the training issues in some detail in your statement. And, Mr Cotterell, you've also made a note at paragraph 19 of your statement of the Minister's correspondence with the deans of medical schools.

So I think the – it's fair to say the Royal Commission is interested in training. But
25 what we have heard about training is a divergence of – well, not so much a divergence – a mix of views, from the need to train the old dog, so to speak, those who have been in the system for a long time and may carry with them all of the cultures and values and attitudes which have been barriers over the past. So that need to address training to unravel unconscious bias.

30 COMMISSIONER SACKVILLE: Better you're looking at the witnesses than at the bench when you say that.

MS EASTMAN: And then there also has been expressed an important need to capture the new generation of medical practitioners, nurses and allied health
35 professionals to say that in the future our up and coming medical profession is going to be enlightened with new values and attitudes, but we start to do that now. One of the things we're interested in the Royal Commission – and I want to explore in terms of the evidence that you give about inclusion of training, curriculum development in this roadmap – is what are you looking at in training and outcomes? How – and there's a couple of questions in this. How do we accommodate the wishes for people
40 to have training that will change attitudes, versus the wishes of some people to say we need to have training that provides a specialist skills and knowledge for specialist

intellectual disability care? So I'm going to open that up to the three of you, but, Dr Singer, I think you've addressed this in your statement.

DR SINGER: Yes. So I'll talk about it in the general context, and Mr Cotterell can chime in if he wants to talk about anything specifically in relation to the roadmap.

5 So there are, effectively, four phases of medical training, what most people would understand as undergraduate, though to point out that a large number of medical degrees now are effectively postgraduate courses. And that certainly is the area where you're hoping to influence a group of young people into developing both the skills and the right attitudes in relation to people with intellectual disability.

10 The next phase is what we describe as prevocational training. So these are junior doctors who are in their early postgraduate years, predominantly working in hospitals. And for most of them this, essentially, is a time to turn the theoretical knowledge that they learnt into practical effect. There is then vocational training, which is training towards one of the specialty qualifications that is available. And in
15 this context I include General Practice as a specialty. And then – and that leads to a fellowship of one of the colleges, which then qualifies you for specialist registration. And then beyond that is what's described as continuing professional development, which, essentially, is a mix of learning new skills, as well as consolidating prior knowledge and maintaining it.

20 So, as you have described, you may have different approaches to each phase of training. So, certainly, in the medical school phase it's going to be largely about helping people to understand, whilst they're there, teaching them how to communicate appropriately, how to work with people with an intellectual disability in a respectful and compassionate way. One would expect that the training that is
25 received at that stage then, essentially, gets turned into a more practical sense as they start their early practice.

And then in both vocational training and in continuing professional development one would expect that it will be a mix of things. So vocational training would certainly be the phase where development of special skills in this area would occur. And
30 generally one would expect that that is going to be part of a program. So I guess there's two aspects, because, obviously, there are skills that we expect every doctor to have relevant to the specialty that they practise in, but also there will be a group of doctors who will have a special interest in helping people with intellectual disability and who will develop a deeper level of knowledge.

35 And then, in continuing professional development, it's more, as the words say – essentially, it's a continuation of that. It's not necessarily the case that things have to be radically different between one phase to the other. Certainly, you know, an appropriately-created learning module that deals with these issues, and both provides some learning and hopefully encourages practitioners to evaluate their own attitudes
40 and hopefully encourages them to change them in the right direction, would apply to all phases of training.

And certainly, to describe an example from a different place, most medical school – or all medical schools, most of the college training programs now have modules in relation to Aboriginal and Torres Strait Islander health. And those go to both dealing with the particular problems that that population have, but also dealing with attitudes as relates to what is commonly described as cultural safety. So it’s certainly possible for all of that to happen. Generally, it is up to the individual organisation to design their program such that it is consistent with what they’re aiming to do in training.

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MS EASTMAN: So one issue that has arisen is the absence of a specialist pathway or career for people to have expertise just focused on intellectual disability. Is part of the consideration the curriculum development and education and training not only to train people with expertise, but to also find pathways for them in health?

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DR SINGER: Yes, it is. It’s fair to say that having a specialty officially recognised has a couple of particular issues attached with it. So one is, obviously, that of recognition, which generally in the – certainly in the context of Australia means that you get what’s called a protected title. So, for example, if a specialty of intellectual disability physician – and it’s a clumsy way to describe it, but hopefully you understand what I mean. If that was created, then if that was recognised as a specialty, a group of people who trained in that would be exclusively able to claim that they are that.

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The other side of specialty recognition is often that there are some items within the Medicare Benefits Schedule that are restricted in who can use them. And if there were items that were specifically designed for use by a particular group which you weren’t part of, being recognised as part of that group, would give you that access. There’s something that’s maybe a step back from those more formal steps which is, I guess, developing a special interest in a particular area. And there is nothing to stop that happening now. Generally, the way that it develops is that a group of people with a common interest that they regard as distinct from other interests usually form their own society, and through that society, which generally will be aligned with one of the specialist colleges, will then work with that college to develop a training program.

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MS EASTMAN: And an issue that’s also been raised in the area of training and curriculum development is a commitment for funding. And one of the witnesses has told the Royal Commission that their understanding is that the Commonwealth hasn’t made any commitment to funding either a review of existing education and curriculum or what might be a plan going forward; is that right?

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DR SINGER: That is correct. But if I can maybe provide a bit of an explanation. So funding for university medical school courses provided through the education portfolio. We use the generic term of Commonwealth supported places for those. Funding for postgraduate training is a mix. So obviously, the training within hospitals, those doctors – the doctors in training are employed by those hospitals, as

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well as those trainees will pay fees to their respective college, which go towards the administration and support of their training.

5 For doctors training in general practice, the Commonwealth does provide a funding program specifically for general practice training, which is a mix of support for the colleges, the regional training organisations, who support general practice training, the trainees themselves. And, also, trainees have the ability to bill services through Medicare, which other trainees don't.

10 As a rule, the Commonwealth does not provide funding for a – for particular training content, though, certainly, when a particular need is identified, we have often contracted with organisations – usually it's with a college – to develop appropriate content in that way. But it's not a – there's not a broader policy. And to my knowledge we currently don't provide any specific funding in relation to training around intellectual disability.

15 MS EASTMAN: So if training is going to be part of a new way forward, is it the case that any initiatives in training, if they're to be successful, are necessarily going to involve the participation and cooperation of the states and territories, together with the medical schools and together with the relevant colleges; is that right?

DR SINGER: Yes, that's correct.

20 MR COTTERELL: Maybe I could add to that. We have invited the deans of the medical and nursing schools - - -

MS EASTMAN: I was going to ask you have you had a response to the Minister's letter from September from any of the deans yet or the AMC or the Council?

25 DR SINGER: So I can certainly comment. Coincidentally, I was speaking to the chief executive officer of medical deans on Monday. We were at an unrelated meeting, but, certainly, they are very keen to be involved and to look at ways that they can improve their delivery of their training. And I believe the Chair of the medical deans, Professor Simons, has replied to the Minister's letter.

30 COMMISSIONER SACKVILLE: To determine – if this is to be taken further, there are a number of stakeholders, I judge, from what you've said. The Commonwealth can have direct influence under existing practices or programs by, for example, alteration of the Medicare schedule, if it was thought appropriate, for example, to provide benefits for doctors who practised in the area of intellectual disability, assuming there can be appropriate definitions of the services to be provided. But that's one way change of the kind we're talking about might happen.

35 I take it another way is through funding by the Commonwealth. And you've explained that sometimes the Commonwealth does provide funding in relation to the four phases of education that you identified, although it seems to be a little sporadic.

Is there any other way? Have I summarised the position correctly? Is there any other way the Commonwealth can be involved?

DR SINGER: So I think in relation to a particular issue, Commissioner, yes, it can appear to be sporadic. There's certainly - - -

5 COMMISSIONER SACKVILLE: I wasn't meaning to be critical by that. I was just describing or summarising what you have said.

DR SINGER: Sure. So one other thing that I haven't mentioned is a funding stream that's called the Specialist Training Program, which is a stream to provide funding for vocational training in areas outside of the public hospital system. It's designed to be a workforce program. So it's mainly around supporting training in areas that had previously been identified. The particular focus is on rural training and also training in relation to both encouraging Aboriginal and Torres Strait Islander doctors, but also training non-Aboriginal and Torres Strait Islander doctors in being more expert at treating such patients.

15 And, certainly, as part of that program there have been occasionally requests by colleges for some of those funds to be used for a particular training module that they wish to use, consistent with the aims of the program.

COMMISSIONER SACKVILLE: Yes. So for the purposes of developing the ideas that have been discussed, there are actually a number of stakeholders. They are, of course, the Commonwealth, they're the states, because they run the - or they're responsible ultimately for the hospitals. There are the hospitals themselves, there are the faculties of medicine and allied health schools at universities. And there may be some others who are involved in the provision of services who need to be brought into this process, as well. Is that - - -

25 DR SINGER: Yes. That's true. And I would also like to make the point that, again, sort of similar to what we talked about in relation to general practice, that, you know, a general practitioner has a fixed amount of time to do something and what they do with that time can potentially be influenced by what items are available. I think it probably is potentially the same in this space, that it's, yes, there may need to be some extra funds provided, but there is also nothing to say that existing funding from existing training programs cannot be redirected.

COMMISSIONER SACKVILLE: Okay.

MR COTTERELL: Commissioner, if I could assist. I think we've also invited all - almost all of the relevant parties that you suggested to our second Roundtable. I would expect that we would have a significant stream of discussion about how to take that work forward there. And we - and I hope we agree on a process for taking that forward there.

COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: Can I turn to an element - - -

COMMISSIONER SACKVILLE: Ms Eastman, I'm just wondering should we have a break at some stage or do you wish to finish with our three witnesses?

MS EASTMAN: I was going to try to finish by 3.

5 COMMISSIONER SACKVILLE: Okay.

MS EASTMAN: And then have a break then, if that's convenient.

COMMISSIONER GALBALLY: Just before we move on, I'm very struck by the really excellent work that's being done to recruit Aboriginal doctors. And I think it would be the case that, in this space, to have people with disability as doctors would also be very helpful, you know, as role models. And, as far as I know, there has been nothing done – in fact, I have heard about barriers, you know, that if you want to do something specialist in this area, for instance, you can't – if you can't – if you're not dextrous enough to do the surgery component. And I wondered if that could also be – whether you think that's an area that should be thought about?

15 DR SINGER: So, certainly, I know that the – the medical deans have had a subgroup for a while now looking at this issue, particularly in relation to both admission and support through medical school. And – and I certainly know of a number of anecdotes of, not people with intellectual disability, but certainly people with – with other disabilities who have been able to successfully complete a medical school course.

20 It becomes a bit more difficult in relation to – to specialty fields of – of practice. Inevitably, there are fields of practice that require particular skills, which a – which a disability may prevent you from being able to – to practise to the full extent. But fortunately, medicine is a fairly broad field and there are lots of opportunities, certainly, a – an anecdote about – about a person who I – who I do know, who was a partial quadriplegic as a result of a – of a – of an accident that happened whilst they were in medical school, they did manage to complete their degree and, subsequently, was going to go into one field of specialist training but decided on – on another that was more relevant, and they've successfully completed that.

30 COMMISSIONER GALBALLY: So there are scholarships especially designated and a really active recruitment process?

DR SINGER: No – I – no, I'm not aware of any scholarships as – as such, as you've described. There certainly are those available in relation to Aboriginal and Torres Strait Islanders, not, as far as I'm aware, in relation to people with a disability.

35 MS EASTMAN: Can I ask you about the research data and measurements to support continuing improvements. So back to the Roadmap. This is page 11. It doesn't have a particular element number, but it's at the bottom of that page. And

data research and measurement are issues that the Royal Commission has heard some evidence about during the course of the past week or so. And what I wanted to ask you here is there's a dot point which says:

5 *Building a national data asset on the health of people with intellectual disability.*

So this would be a Commonwealth initiative; is that right?

MR COTTERELL: This is one of those areas that we discussed very briefly at the Roundtable. It was agreed that it was important and it was put on the agenda. We would need to have a lot of further discussion about how it's taken forward.

10 MS EASTMAN: All right. So that hasn't really developed beyond just saying, "We think research data and measurement are important."

MR COTTERELL: That's right. But, I would – again, I would hope that would develop further at the second roundtable and we would have a process of the relevant experts continuing that work.

15 MS EASTMAN: We heard some evidence this morning about New South Wales, I think, conceding that there are some difficulties in terms of the collection of data, and then the ability to do and undertake – undertake an analysis of the data. Is this an issue that has caused concern to the Commonwealth?

20 MS RISHNIW: So perhaps if I can answer that. The – the collection of data and the analysis of data, in looking at any data that is collected at both Commonwealth and, I would imagine, at State level, one of the things that the Commonwealth always balances is the – the need to collect data with privacy considerations for individuals. And the cost of the – and the kind of tensions and trade-offs around collecting data, but also particular population groups being subject to data collection intensely.

25 The Australian Institute of Health and Welfare, which is the Commonwealth's premier health data agency, is tasked at the moment with collecting a national disability data asset, and is weighing up all of those issues. I would imagine, and our experience with working across the health system with State Governments, means it can't just be a Commonwealth data asset. It will need for – for comprehensive coverage would need to involve States and Territories.

30 MR COTTERELL: All right. Could I briefly add to that. It would also need – probably need to involve the National Disability Insurance Scheme data and some linkage with health data, which is always difficult.

35 MS EASTMAN: Then, finally, you've got other considerations. And there's two dot points. There may be some assistance from the evidence of the Royal Commission. And this is not what the Royal Commission might be having in mind, but just listening to the evidence over the time, dental and oral health care seem to be

a very significant issue which I hadn't seen identified expressly in the roadmap. Would that be an area that requires attention at a Commonwealth level?

5 MR COTTERELL: So the – the Commonwealth and the States share responsibility for dental services. The Commonwealth provides two streams of funding for dental
10 services for public dental services are delivered by the States and Territories. We do need to look at this issue. We have invited the Australian Dental Association to our second roundtable – and I can't remember the other name of the organisation – but a more expert organisation on dental needs of people with disability. And so I expect we would need to address that work. It's an area of preventative health which is
15 really important. So we need to find the right place in which to progress that work, but absolutely needs to be looked at.

COMMISSIONER SACKVILLE: Does the Commonwealth have any influence or control over the benefits provided by the medical funds for dental services when they issue their extra cover, or whatever the additional cover is called, in any particular
20 case?

MS RISHNIW: We – we don't have direct influence over the types of cover or the coverage within private health insurance products that are offered. But, certainly, the Commonwealth works with private health insurers and looks at reasonable products. So some of the changes to private health insurance most recently looked at the
25 benefits of particular groups of products. But the Commonwealth doesn't specify what coverage should or shouldn't be provided.

COMMISSIONER SACKVILLE: The reason I ask is that my experience may be limited, but the impression is that the – there is a very great gap between the benefits that are available and the actual charges that are levied by a dentist.

25 MS RISHNIW: And I think it – it goes to one of the issues. And Mr Cotterell has raised the need to look at that and, certainly, we've been listening closely to the evidence around, particularly, dental issues for people with an intellectual disability. I think it goes to some of the challenges of making sure that we are working with the State Governments on these issues, but also, kind of, the – the costs involved with
30 generalised dental care.

COMMISSIONER BENNETT: We also heard evidence, only from one particular parent, but saying they had had their child on private health insurance during that child's – until 25. And then the health – the private health insurer would not take – would not allow that young woman to then have private health insurance because of
35 a pre-existing condition. I don't know if you can add any light to that or consider it and maybe come back to it, but it did seem, while other people didn't raise private health insurance, it was a particular issue for someone who had provided that until the person had reached the 25 year threshold and then was denied access through the private health insurance.

MR COTTERELL: It sounds to me like they were on family cover of some kind - - -

COMMISSIONER BENNETT: Yes.

5 MR COTTERELL: - - - and the age limit was reached and then they needed to get individual cover and, at that point, private health insurers are able to apply this pre-existing condition. So – and – but none of us here are directly responsible for private health insurance so we will take that away - - -

MS RISHNIW: And have a look at that.

MR COTTERELL: - - - and come back.

10 MS RISHNIW: Yes. And, obviously, we can't comment on the individual circumstances of that particular, but - - -

COMMISSIONER BENNETT: But you might want to have a look at the evidence that was given.

MS RISHNIW: - - - we will have a look at the evidence.

15 COMMISSIONER BENNETT: Yes.

MS EASTMAN: Other issues included palliative care. And one that I wanted to ask you was about the concept of reasonable adjustments. So we see this language of “reasonable adjustments” in Commonwealth material, but also in State and Territory material. And I assume that that’s to reflect a legal obligation that arises in the
20 Disability Discrimination Act or other sources; is that right? Is that something that you’ve reflected on, about the need to have some clarity around legal obligations of reasonable adjustments, and whether this Roadmap needs to be supported by any other legislative change?

MR COTTERELL: I think we could take a look at that issue. I have palliative care
25 in my areas of responsibility. Again, there’s a shared responsibility between the Commonwealth and the States, and the Commonwealth does some national projects, and the States provides specialist services. How that all works together to avoid the sorts of situations that have been described in the evidence, we could have a look at as – as part of the Roadmap.

30 COMMISSIONER ATKINSON: But while we’re on that, obviously, palliative care physicians like to get their patients early. But the evidence – so that they can have a proper plan – but the evidence that we heard suggested that they’re getting some patients with intellectual disability inappropriately early, and that’s a matter you could look at?

MR COTTERELL: I think we would look at the evidence that's arisen from the – from the Royal Commission. It was shocking evidence.

COMMISSIONER ATKINSON: Thank you.

5 MS EASTMAN: If that's a convenient time? Our planning for the afternoon is if we could have a break for, say, 10 minutes. Then I will do my best to complete the Commonwealth evidence in about 15 to 20 minutes. And then our final witness can give his evidence, Mr Head from the Commission.

10 COMMISSIONER SACKVILLE: Good. All right. Thank you. I've just got one question. The taskforce that looks at this Royal Commission, what does that actually do?

MS RISHNIW: So the task - - -

COMMISSIONER SACKVILLE: Keep an eye on us, or what?

15 MS RISHNIW: The taskforce has been set up in the department to really support us in providing you with the most comprehensive and the best responses that we can, and preparing statements that cover the whole of the department, particularly given the size of the health system and the size of the department.

COMMISSIONER SACKVILLE: Thank you. We will adjourn for 10 minutes.

20 **ADJOURNED** **[3.02 pm]**

RESUMED **[3.15 pm]**

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

25 MS EASTMAN: I've finished asking about the roadmap. And then, in the course of talking about the roadmap, we've touched upon quite a lot of issues. Is there anything else that I have overlooked that you wish to tell the Royal Commission about the development of the roadmap that I haven't covered? Maybe too tired to remember.

30 MR COTTERELL: Perhaps if I could just conclude. We're very much looking forward to our second Roundtable on 7 April. At the moment, 60-something people will be at that Roundtable. So it's going to be a difficult room – job to manage, but we're putting some thought into how we do that, so that we can at that Roundtable finalise the roadmap and not have the development of the roadmap hold up other work, and potentially have some other processes flowing out of it on specific issues.
35 Some of those we've touched on.

MS EASTMAN: All right.

MS RISHNIW: And, sorry, Ms Eastman, if I can add. I think in developing this roadmap and the future, you know, Roundtable, we're very, very much conscious of listening to people with intellectual disabilities, their families, their carers, their
5 advocacy groups and really partnering with them to develop what is most important for them.

MS EASTMAN: How are you going to do that?

MS RISHNIW: Well, part of it was actually getting together at the first Roundtable and listening and letting them tell us what is most important and urgent for them and
10 looking at who else do we need to invite to the next Roundtable, and taking the evidence absolutely presented to this Commission - - -

MS EASTMAN: Although many - - -

MS RISHNIW: - - - to shape that.

MS EASTMAN: - - - people with intellectual disability who live in closed or
15 segregated environments or they may be in forms of detention. And that's a very vulnerable group, as we understand, from the evidence. How will you reach out to people in closed settings to ensure that you hear their voices?

MR COTTERELL: I think we need to talk to our colleagues in the National Disability Insurance Agency and the Department of Social Services about how we do
20 that, but they'll be involved in this work.

MS EASTMAN: All right. So I understand from the evidence is there's an intention and goodwill to do that, but the mechanics about how you find some of the most invisible people and most vulnerable people is still a work in progress; is that
25 right?

MR COTTERELL: That's right.

MS EASTMAN: Okay. Ms Rishniw, you have in your statement from paragraph 46 set out a number of action plans that the Commonwealth has developed, and in this part of your statement also identified a range of policies. If we look at those – and I'm not going to go through each of them, but can I deal with them collectively –
30 is that what you've included by way of programs, action plans and policies, some of those policies have application to the whole of the population and some have application to people with intellectual disability in that context of whole population; is that right?

MS RISHNIW: That's right.

MS EASTMAN: And some of the initiatives that you've included in relation to autism, for example – this is paragraph 63 – you refer there to a Commonwealth announcement in October 2007 – so this is some time ago – where there was the announcement of Helping Children With Autism Package, which included \$190 million over five years to assist children with PDD, including their parents and carers. So I just wanted to ask you about this. And you've heard me raise the issue of people living with autism and where they fit in. In terms of this particular initiative, if it was conducted over a five-year period and that commenced in October 2007, is this still relevant to any of the work or the initiatives of the Commonwealth at the present time?

MS RISHNIW: So, as part of that package – and, obviously, it was before my time in the department – there were a number of Medicare Benefits Schedule items that were developed. And those items are still enduring.

MS EASTMAN: All right. And when you say “they're still enduring”, what does that mean? Is the funding ongoing or - - -

DR SINGER: I might be able to comment on this, Ms Eastman. So those items are a series of items. So there's item 135 and 289, which are items for either a consultant physician in paediatrics or a consultant psychiatrist to do a specific task in relation to ensuring the diagnosis of autism. And those items also then allow for ongoing access to a short series of allied health interventions to help with developing a care and treatment plan.

So all of those items have been reviewed as part of the Medicare Benefits Schedule review that's currently going on. And certainly – and I provide support to that review. And I can say that all of those items have ongoing support from the MBS Review Taskforce and stakeholders. And, in fact, there's been some preliminary discussions about the potential of extending some of those items. Like, for example, item 135 currently has an age limit applied to it, which we are looking at the possibility of extending.

MS EASTMAN: All right. Now, at paragraph 69 under the heading Sport, you refer to some budget announcements for 2019 to 2020 of the Australian Government being committed to funding sport and physical activities to include – to support inclusive sport. And then you set the initiatives out on the following page. Why did you include these initiatives in the context of your statement for an inquiry by this Royal Commission into the health of people with intellectual disability?

MS RISHNIW: So, in terms of the notice that I received, and its comprehensive nature and the comprehensive nature of the definitions used by the Royal Commission, I wanted to provide a statement that could be as comprehensive as possible. In terms of sport, it is a responsibility within the Department of Health. And, obviously, it's one element in broader preventative health. And these items I drew out specifically because they dealt directly with people with a disability.

MS EASTMAN: All right. Now, one – looking at all the policy initiatives and action plans that you’ve identified, you haven’t referred to the National Disability Strategy 2010 to 2020 in your statement. Was that for any reason?

5 MS RISHNIW: I focused primarily on the strategies that are the responsibility of the Department of Health and its portfolio agencies. The National Disability Strategy is developed by the Department of Social Services and with the National Disability Insurance Agency as part of their responsibilities. So that’s why I didn’t cover it here.

10 MS EASTMAN: We have heard some evidence that the National Disability Strategy does touch upon the area of health. And is there any aspect of the delivery of that strategy that is within the Health portfolio at all?

MS RISHNIW: I would need to take the detail – I don’t have the detail of the National Disability Strategy in front of me. But, insofar as any actions relate to the Department of Health and the responsibilities within the department, I would expect

15 that to be covered through consultation between departments.

MS EASTMAN: All right. I want to next ask you about the My Health Record. And the Commissioners have had some questions about the My Health Record. And you’ve addressed this at paragraph 45 of your statement. And there’s a lot of information in that one paragraph, but I wanted to ask you about the relevance of the

20 My Health Record to the Commonwealth’s role in improving the health outcomes for people with intellectual disability. What does the Commonwealth see as to the way in which the My Health Record should operate to support people with intellectual disability?

MS RISHNIW: So My Health Record is a government initiative that provides an

25 electronic health record to every Australian who wants one. In 2018, the government went through a process, after significant consultation, of an opt-out process, which means the government was going to create a My Health Record for every Australian who didn’t opt out of having a My Health Record. In November 2018, over 20 million records were created electronically. My Health Record aims at a national30 level to provide electronic health records for Australians that are consumer-controlled.

A person can determine whether they put restrictions on the information that is included in their electronic health record. But it recognises the fact that collecting information, and particularly with – for people who have multiple conditions,

35 multiple comorbidities, are on a range of drugs or pharma-copy for their conditions is collected in one place for them to control and make it easier for them to explain to their medical professionals what’s gone before their medical history and how to take account of their treatment.

MS EASTMAN: We’ve heard evidence over the course of the past week or so

40 about two things concerning health records. First, the difficulty for parents and

carers to be able to access health records and not receiving copies of reports or having to put in freedom of information applications to access health records. Is this an issue that could be resolved through the My Health Record scheme?

5 MS RISHNIW: That's certainly the intent of the My Health Record scheme, to provide comprehensive health information for the individual that they can control and that they can have their health practitioners reference quickly, easily in a format that's understood, with common standardised medical terms. The Commonwealth is working with the States and Territories on a national digital health strategy that looks at integrating electronic information that's collected at the state level, but particularly
10 in hospitals, for example, into the My Health Record.

But I'm sure you would understand that My Health Record has come in, there's a range of different information technology systems that vary from jurisdiction to jurisdiction. And so making sure that we have interoperability of systems, so information can be translated between systems into My Health Record, that we have
15 secure messaging, that the information is provided with the utmost information patient privacy in mind is work that means standardising and making sure everyone's information technology and digital technology is compliant and conformant.

MS EASTMAN: Well, one of the issues, of course, for a person with intellectual disability is also the ability to navigate concepts of privacy and giving permission for
20 people to access those records. Is there anything, to your knowledge, about the way in which the My Health Record has been developed that specifically takes into account the circumstances of people with intellectual disability and, more broadly, cognitive disability?

MS RISHNIW: The My Health Record Act 2012 allows for a person to designate
25 an authorised representative.

MS EASTMAN: Well, if I have an intellectual disability, how am I going to do that?

MS RISHNIW: So, depending on the extent of your disability, you can choose someone who's your authorised representative. You can choose someone, say, for
30 example, who is a guardian, who is a family member, who is a carer, and actually go through and nominate that person. If you have disability, that means you can't necessarily make those decisions for yourself and you have a guardian acting for you - - -

MS EASTMAN: So I would have to, perhaps, make – have somebody make an application to a guardianship tribunal to get an order from a tribunal to authorise
35 somebody to access My Health Records to assist me navigate the health system?

MS RISHNIW: So you wouldn't have to go to a tribunal; you can nominate an authorised representative, if you're able to do that.

MS EASTMAN: But if I can't?

MS RISHNIW: If you can't, My Health Record recognises someone who is already in a position of a legal guardian, so you wouldn't have to apply to a tribunal. They would have to demonstrate that they have your permission and they are a legal guardian or a person who is able to make decisions on your behalf.

MS EASTMAN: Could you appreciate that – and I'm not being critical, but the description you've just given is highly illustrative of the barriers for people with intellectual disability to navigate the health service. So to even get through the door of ensuring that the health records are accessible seems to be a barrier.

10 MS RISHNIW: So the system is trying to reduce those barriers and reduce the barriers for you to have to apply to each of your medical professionals to get access to those records. But certainly we can ask the Australian Digital Health Agency to look further into how to make accessibility to those records easier for people with intellectual disabilities, while being cognisant of privacy concerns.

15 MS EASTMAN: I would have assumed that this is something that would have captured the Commonwealth's attention in relation to the growing population of people with dementia and what we know about that cohort like – being likely to increase into the future. Are there any particular arrangements in place for a person with dementia, in terms of the way in which the My Health Record would operate?

20 MS RISHNIW: Once again, not specifically to dementia, but around authorised nominee to be able to access and operate your My Health Record on your behalf - - -

MS EASTMAN: All right.

MS RISHNIW: - - - would apply.

25 MS EASTMAN: The other issue which has arisen is for families with children with intellectual disability or cognitive disability and that transition from paediatric care to a more diffuse adult model. Has there been any consideration in the My Health Record scheme to that transition from paediatric care to adult care generally and, then, more specifically, for children with cognitive disability?

30 MS RISHNIW: So I will be able to deal with some of the aspects of that and I may need to provide further detail later for the Commission. But, certainly, the My Health Record Act recognises children – parents have access to their child's My Health Record up until, I think, it's the age of 14 years of age. At that point, adolescents can choose to take – they take control of their My Health Record. They can choose for their parents to continue to exercise their authority in accessing their My Health Records. Once again, in terms of the issues around children transitioning from childhood into adolescence, particularly with cognitive disability, it really relies on that authorised nominee to be able to access your My Health Record. But I will need to take more specifics on that as well.

35

MS EASTMAN: All right. The final matter I wanted to ask you was about policy in relation to First Nations People with intellectual disability. And we had some evidence from Dr Scott Avery earlier in the week in terms of some research that he has undertaken. And we have come across, in preparing and reviewing the material
5 you provided us with, a Department of Health implementation plan for National ATSI Health Plan 2013 to 2023. And that was developed in 2015. Is that something you're aware of?

MS RISHNIW: I am.

MS EASTMAN: And to the extent that that national plan focuses on the health of
10 First Nations People, to what extent does that include specific issues for First Nations People with cognitive disability?

MS RISHNIW: That plan was developed in consultation with Aboriginal and Torres Strait Islander people and an implementation plan sits under that. It also has a national Aboriginal and Torres Strait Islander leadership forum that helps guide that
15 implementation. In terms of specifics for Aboriginal and Torres Strait Islander People with a cognitive disability, the plan takes a comprehensive health approach for Aboriginal and Torres Strait Islander People, recognising placing the individual at the centre of their care and trying to provide supports that recognise them being at the centre of their care without distinguishing any particular disabilities, but making
20 sure that the system responds to that. So I'm not aware of any specifics in those plans that directly deal with Aboriginal and Torres Strait Islander People with a cognitive disability, except to say the plan is intended to be comprehensive in its nature.

MS EASTMAN: And how will that plan, which takes us out to 2023, fit within the
25 Roadmap that we've spent some time on today?

MS RISHNIW: So I think Mr Cotterell mentioned, you know, both the primary care and the preventative health 10-year plans. And the aim is for complementarity and making sure that all of these plans, while they may focus on, you know, specifically,
30 actions that will make the greatest difference for people with an intellectual disability, recognise they fit within a broader system and a broader framework.

MS EASTMAN: Okay.

MR COTTERELL: If I can just add.

MS EASTMAN: Yes.

MR COTTERELL: I would expect, going forward, that we handle these issues in a
35 complementary way in both places. So, both in the Aboriginal and Torres Strait Islander Health Plan Implementation Plan – that's a lot of words – and in the National Roadmap. So we – we might be duplicating those things, but it will be the

same actions in both places so the relevant people could identify that their health was being addressed.

MS EASTMAN: Thank you. Commissioner Atkinson.

COMMISSIONER ATKINSON: Could I ask a question about, particularly,
5 Aboriginal and Torres Strait Islander People? Subsequent to that plan, of course, we've had the Royal Commission into Juvenile Detention in the Northern Territory, and you're probably aware that unrecognised and undiagnosed cognitive disability is a huge issue which leads to the over-representation of, particularly, Aboriginal
10 children in juvenile detention and, inevitably, then, in imprisonment. So is there any plan for the Commonwealth to deal with that as an issue in terms of the health of people – Aboriginal and Torres Strait Islander people?

MS RISHNIW: So, once again, in terms of looking at the implementation of the health plan and looking at how we work with Aboriginal and Torres Strait Islander
15 People around early diagnosis, the relevant supports, particularly with the cognitive impairment, certainly there has been programs around fetal alcohol spectrum disorder that often is associated with, particularly, early incarceration and unnecessary incarceration. We're well aware of that. It's an area where we need to work with State and Territory governments who are responsible for the justice
20 system and the gaols in their States and Territories.

COMMISSIONER ATKINSON: Sure, but – sorry, if I could interrupt.

MS RISHNIW: Yes.

COMMISSIONER ATKINSON: It's too late then, isn't it? Once the person is in
25 detention, the system has failed. It has failed to pick them up as children, provide them with adequate health care, adequate education, so they don't end up in the juvenile justice and then adult imprisonment system.

MS RISHNIW: And one of the elements of the Aboriginal and Torres Strait
30 Islander Health Plan is specifically looking at the first 2,000 days, which goes preconception through to development of – of children and working with young women, in particular, on making sure that we're picking up, particularly, the biggest impact on young people's development and young people's cognitive development at those first 2,000 days from conception through to birth and through to the first three
35 years of life, which will make a huge difference.

MR COTTERELL: If I could assist. The relevant area of the department is, even
35 more than me, in continuous consultation with the Aboriginal and Torres Strait Islander health sector about all of those issues. So I would be very surprised if it – if it weren't covered in their implementation plan.

MS EASTMAN: Thank you, Commissioners. Unless Ms Morgan has any questions or there's any further questions, that concludes the evidence.

MS MORGAN: No, thank you.

COMMISSIONER SACKVILLE: Dr Singer, Ms Rishniw and Mr Cotterell, thank you very much for your detailed statements and for your evidence. Please pass on our thanks to the taskforce as well.

5 MS RISHNIW: I will. Thank you.

<THE WITNESSES WITHDREW [3.38 pm]

10 MS EASTMAN: Commissioner, we just need to do a very brief reorganisation of the bar table. So could we ask you for a three to five minute break, and then we may need to sit till about quarter past 4.

COMMISSIONER SACKVILLE: Yes. Well, we will give you four minutes.

15 **ADJOURNED [3.38 pm]**

RESUMED [3.45 pm]

20 COMMISSIONER SACKVILLE: Mr Head, thank you very much for coming to the Commission and for your extremely detailed statement. If you wouldn't mind taking either the oath or the affirmation as you wish.

<GRAEME HEAD, AFFIRMED [3.46 pm]

25 **<EXAMINATION BY MS EASTMAN**

COMMISSIONER SACKVILLE: Thank you, Mr Head. Yes, Ms Eastman.

MS EASTMAN: Mr Head, thank you very much for waiting during the day. We're a little running behind time and that's entirely my responsibility. So thank you for your patience. So you are Graeme Head?

30 MR HEAD: Yes.

MS EASTMAN: And you are the Commissioner for the National Disability Insurance Scheme Quality and Safeguards Commission?

MR HEAD: I am.

MS EASTMAN: And you have prepared a statement for the Royal Commission dated the 11th of February.

MR HEAD: Yes.

5 MS EASTMAN: And you have read that statement.

MR HEAD: Yes.

MS EASTMAN: Are there any amendments to the statement?

MR HEAD: There is one amendment in paragraph 252, I think.

MS EASTMAN: All right.

10 MR HEAD: Which has - - -

MS EASTMAN: Is it 251 or 252?

MR HEAD: 252 has an incorrect reference – cross-reference. It should refer to paragraph 251 and it refers, instead, to paragraph 246.

MS EASTMAN: All right. So where there's a reference in – so page 52, paragraph

15 252, the references to paragraph 246(a) should be a reference to paragraph 251.

MR HEAD: Yes. And, equally, the reference to paragraph 246(b) should be a reference to 251(b).

MS EASTMAN: All right. So if those changes are made, so to substitute 246(a) and 246(b) and change that in both places to 251.

20 MR HEAD: Yes.

MS EASTMAN: With that amendment, are the contents of the statement true and correct?

MR HEAD: Yes.

MS EASTMAN: Now, your statement is very lengthy and there's a large number of

25 issues addressed in your statement. In the time that we have available this afternoon, I want to focus on some quite specific issues. In doing so, that's not to overlook the range of issues that you've addressed, and it may be that we will come back to them at some later point in time.

COMMISSIONER SACKVILLE: And also, I should say that your outline of how the scheme works from your perspective is extremely helpful. Thank you for that.

MR HEAD: Thank you.

5 MS EASTMAN: And I – and I will raise this now, but I understand that you are aware that there was some evidence given yesterday by Ms McKenzie and Ms Porter that you wanted to address. And you’re content to provide some material to the Royal Commission, either a submission or further statement; is that right?

MR HEAD: Yes, that’s correct.

10 MS EASTMAN: To address some of those issues. Well, let’s start. You say in your statement, at paragraph 7, that you’ve taken up the inaugural position as Commissioner. And you were appointed to the position in December 2017 and then took up office, is that right, on 1 July 2018?

15 MR HEAD: I took up the statutory office on the 1st of July 2018 and, from late January 2018 until the statutory office commenced, I worked in an offline capacity in the Department of Social Services to work with the team in the department who were establishing the Commission.

MS EASTMAN: And in your statement, you set out the role and the jurisdiction of the NDIS Commission.

MR HEAD: Yes.

20 MS EASTMAN: And you set out your particular responsibilities; is that right?

MR HEAD: Yes, that’s correct.

MS EASTMAN: So there was an activity report released earlier this week; is that right?

MR HEAD: That’s right.

25 MS EASTMAN: And this might be, Commissioners, a helpful way in to some of the issues that Mr Head is responsible for. So a copy of the activity report, for the period 1 July 2019 to 31 December 2019, is in part D of the tender bundle at tab 189. And we will bring up some of those graphics on the screen. So I’m going to do it this way because, Mr Head, it seems to me – and please correct me if I’m wrong –
30 that the information contained in the summary report will give us a snapshot as to how the Commission is performing at the present point in time and the types of issues coming to the Commission; is that right?

MR HEAD: Yes. It gives a snapshot, really, of the levels of activity in relation to various of our functions and how that’s developing over time.

MS EASTMAN: All right. So if we can bring up page 1. And, Commissioners, you might have that on your screen.

COMMISSIONER SACKVILLE: Yes, we do, thank you.

5 MS EASTMAN: So, first of all, the infographic identifies the participants across Australia. And this includes participants other than in Western Australia; is that right?

MR HEAD: That's correct.

MS EASTMAN: So Western Australia is coming online in July this year; is that right?

10 MR HEAD: That's right. It's the third stage in a – in the evolution of the framework with New South Wales and South Australia in the first year, everyone else but Western Australia on 1 July last year, and WA coming in 1 July this year.

MS EASTMAN: And over the period 1 July 2019 to 31 December 2019, just looking at this infographic, are you able to say to the Commissioner what the percentage of increase in participants has been?

15 MR HEAD: I could certainly find that information for you, but I didn't prepare information on the percentage increase for participants. Really, the way the scheme works, we get participant data from the National Disability Insurance Agency. We provide, to the wider world and also to the agency, the data on providers, because it's providers we regulate. So – but I would be able to source that information. Participant numbers are published quarterly by the NDIA in their quarterly report and are publicly available for the same time period.

MS EASTMAN: Right. And number 2 on the document, the infographics, has some information about complaints. So you set out in your statement that the Commission can receive complaints. And, just for the benefit of those following us, what is the subject matter of complaints over which the Commission has jurisdiction?

MR HEAD: So the complaints function allows us to receive complaints from anyone about the quality or safety of supports that are being provided to an NDIS participant, complaints can be made about both registered and unregistered providers. And the complaint could range from, you know, anything, really, an issue that a person has with the way they're being communicated with, to allegations of quite serious misbehaviour by a provider.

30 Some things that might be the subject of a complaint might also trigger the requirement for the report of a reportable incident by a registered provider. So, as you can see in the infographic – or in the component in the top right-hand corner, about two-thirds of the complaints we receive come from either a person with a

disability or from a family member or friend. There's been quite a lot of work to encourage people with disability to speak up about things that are happening. And it's a bit too early in this dataset to be certain about this, but certainly anecdotally we think that we're starting to see some signs that people with disability are increasing
5 as a proportion of complainants about those things they're experiencing.

MS EASTMAN: All right. Well, just while we're on that looking at that infographic, you've got 38 per cent of people with disability being complainants. Do you know or do you have a breakdown of the number in that 34 per cent who are people with cognitive disability?

10 MR HEAD: I don't think we capture that level of data yet. The Commission is still – well, it's 20 months old, this weekend. Most of the work we've been doing around system development has been around the enablement of all of the key functions that we perform under the Act. We have a program of work in place which is around
15 building our data asset and, really, allowing us to move from a kind of basic start-up phase around data to a stage of development that allows us to do quite specific work and quite sophisticated data analytics. So at this stage, no, but we are doing quite a lot of work around building our data and analytics capability.

COMMISSIONER SACKVILLE: Do we know what proportion of all participants in the NDIS are people with cognitive disability or intellectual disability?

20 MR HEAD: I think the breakdown of the NDIA's participant data has that information. I don't have that information in front of me, but I think that is information that is reported by the agency.

MS EASTMAN: You've said that you've sought to encourage people with disability to be able to make complaints. And I wanted to ask you about an aspect
25 that you address in your statement at paragraphs 109 to 118. And so keep the infographics up, because I'll come back to that. But in terms of specific engagement with people with intellectual disability, either to engage with the Commission generally or, more specifically, for people with intellectual disability to be able to understand how to engage with the Commission to make a complaint, what are the
30 current strategies and/or policies in place to assist people with intellectual disability to be able to make complaints to the Commission?

MR HEAD: So we do a wide range of things. I guess, central to that is that the Commission, because it's new and because the arrangements it's putting in place are quite different and quite a bit more comprehensive than the arrangements that have
35 been in place previously in States and Territories. We have been very present in a range of forums around the country. So we do - - -

MS EASTMAN: What does being present mean?

MR HEAD: Well, we turn up. We do a lot of work with existing organisations that work in the area of intellectual disability and all areas of disability. We make senior

people available to talk at events. We do formal engagement with organisations around the resources we're developing. We do quite specific work around making sure that there are good Easy Read versions of publications we develop. On some of our more sophisticated resources, like the worker orientation module – it's referred to in my statement – people with disability, essentially, deliver that module. The component that relates to the code of conduct is, in the main, presented by people with intellectual disability. And there were people with disability who were part of the production team for that resource, as well, I understand.

5
10 MS EASTMAN: I think it's been suggested that there needs to be some comprehensive support and education for people with intellectual disability to enable them to engage with the Commission. Has there been anything specific developed in relation to support and education for people with intellectual disability?

MR HEAD: So parts of our – 'If you need to speak up, speak to us' campaign, which is, really, the initiative that is about encouraging people to complain, there are components of that campaign that provide Easy Read resources. Our staff who work in the contact centre and our complaints officers receive training. We've done quite a lot of work with advocates to reach out to people with intellectual disability. We've run quite structured forums with advocates from around the country. Those forums have had extensive involvement from people with intellectual disability in those forums. The Commission is still in its early period, but it's been, I think, generally seen to have been very active in trying to contact a wide range of groups across the broad spectrum of disability, including people with intellectual disability.

20
25 MS EASTMAN: Is it the case that the Commission also expects that registered NDIS providers will support people with disability to understand how to make a complaint directly, either to the provider or to the Commission?

MR HEAD: Yes. There are formal requirements for registered providers to comply with practice standards, but also to have in place incident management systems and complaint systems. So the requirements together put an obligation on registered providers to support people to make complaints to them and to make sure that people are supported if they either prefer to contact us or, for whatever reason, don't want to deal with the provider, that they're made aware of the Commission and its role.

30
35 So providers have an obligation. And that's complemented by the fact that we've done a lot of direct reaching out to participants about how to complain. There was a very extensive program of preparation for the second wave of transition when the five additional states came in in July this year of going out to participants, including participants with intellectual disability with resources, that explain who we are, that we're here for them, that we're here for them whether or not they're using registered providers or unregistered providers and that we can take action on complaints.

40 MS EASTMAN: How does the Commission know or monitor whether a provider, registered or unregistered, actually has a complaint system in place?

MR HEAD: So through the audit program that attaches to registration. So the way we have managed transition – and this relates currently to around 18,000 registered providers – providers transition into the Commission through the use of transitional roles - - -

5 MS EASTMAN: I just want to – sorry to cut you off. And I’m conscious of the time.

MR HEAD: Okay.

MS EASTMAN: I just want to know how you do the audit. So - - -

10 MR HEAD: The requirements are expressed through the practice standards and the rules that the standards are a part of. We appoint auditors, we have an arrangement with the joint Australian New Zealand Accreditation Scheme. They recommend suitably qualified audit bodies who can audit on our behalf. We appoint those bodies and we train the auditors. The Commission trains the auditors in the practice standards.

15 MS EASTMAN: Has there been any audit done to date?

MR HEAD: Yes. As providers transition, they’re given a specified timeframe within which they have to commence an application to re-register. It’s that process that assesses them against the practice standards. And we then determine, based on the audit and on a suitability assessment, whether or not we will re-register people. I

20 MS EASTMAN: According to the infographic on the next page, as at 30 June 2019, there were 8,302 providers. As at 31 December, there’s 18,384 providers. So there’s been a significant increase in registered providers over the previous six months; is that right?

25 MR HEAD: The first tranche of registered providers came in on 1 July 2018, two states. And then on 1 July 2019, five more jurisdictions came in. And that’s the principal spike in providers. And we will see another bump on 1 July 2020 when WA comes in.

MS EASTMAN: So it’s stepped through over - - -

30 MR HEAD: It is stepped through over three years.

MS EASTMAN: Right. So if at the current time, or if as at end of December last year, you’ve got over 18,000 registered providers, how many audits would have been done in relation to those providers for a review or audit of their complaint processes?

35 MR HEAD: So the audit – the transition of registered providers, in addition to being phased over three years, is phased based on the recency of audits that providers had

had in their previous system in States and Territories and a range of other matters, so that we prioritised the auditing first of those providers that may be providing the most complex supports. All transition providers have to be through the audit process within a timeframe that's specified on their certificate of registration. So it's – I
5 don't have the exact number that are completed at the moment, but it's in the, I think, several thousand have already completed, but they must complete that process within a specified timeframe.

MS EASTMAN: All right.

10 MR HEAD: And the idea is that, at the end of the 12 months after WA comes in, everybody who's in the system who's registered will have completed the transition and have been audited against the practice standards, and we will already be in the mid-cycle review for the people who came in first.

MS EASTMAN: So going back to the first page of the infographics, you set out percentages of complaints. It's a little difficult to understand what the percentage is
15 of a total. So how many complaints in total?

MR HEAD: So for that period, 2,022.

MS EASTMAN: And so the percentage – half of those complaints were about provider practice. What does that mean?

20 MR HEAD: So that could mean the way the – well, it could mean anything about the way the provider approaches delivering the supports, whether or not support workers are routinely late, whether or not they work properly with people around their preferred times for doing things or whether the person with the disability is being expected to fit in with the support worker. There's a wide range of things that – that are categorised. As I've said before, we will get more specific in how we
25 present the data and count things going forward, but, really, anything that the provider is doing other than those things that are represented in the other categories is counted in provider practice.

MS EASTMAN: And 12 per cent of those complaints are concerned with alleged abuse and neglect. Are you able to help the Royal Commission understand about
30 some of the allegations or the nature of abuse and neglect? What meets that category?

MR HEAD: So what's counted in there are anything where the complainant says that they – they want to make a – a complaint about abuse or neglect, and it can range from quite serious allegations that may warrant, if it's a registered provider,
35 would also trigger a report of a reportable incident, or it can relate to things where a person feels that they've been treated unfairly but – but are not allegations of a more serious nature. So where a person tells us that they feel neglected or abused, that is counted there. Registered providers have unique obligations where there are allegations of abuse and neglect to report those matters as a reportable incident.

MS EASTMAN: And is the categorisation of those four areas of complaint done by the Commission or is that done by the person making a complaint? Do they have to identify in a particular way?

5 MR HEAD: It's done by the Commission. I mean, really, we're trying to encourage people to complain. It's well known that there has been a long history of people feeling not supported and not comfortable to complain. So the idea, really, is to try and have processes that encourage people to speak up and for us to do the sort of back end of that work. This is a fairly basic form of analysing the complaints data at the moment, and I – as I've said before, it's a sort of rapid work in progress what
10 we're doing in the data space.

MS EASTMAN: Is there an overlap between complaints and reportable incidents?

MR HEAD: There can be. So something might be the subject of a complaint from more than one person. You could have a person with disability complaining on their own behalf or a family member or a worker, or all three, and that might also be an
15 incident that has required a registered provider to lodge a reportable incident notification. So there can be the same thing recorded multiple times. And, in fact, if it's a reportable incident notification, you could have more than one notification of the incident as well.

MS EASTMAN: So 2,200 complaints but - - -

20 MR HEAD: 2,022. Sorry.

MS EASTMAN: But 69,397 reportable incidents.

MR HEAD: Yes.

MS EASTMAN: So there's a significant gap, isn't there, between complaints and reportable incidents?

25 MR HEAD: Yes.

MS EASTMAN: So reportable incidents are made by an NDIS registered provider; is that right?

MR HEAD: There's a requirement under the Act. And I think you referred in earlier evidence to the definition of a "reportable incident" that we'd included in the
30 statement. So registered providers are required to notify us of certain things. A very important component of the reportable incident notification process relates to the use of restrictive practices and - - -

MS EASTMAN: I want to ask you about that. You've got – and if the infographics now go to point 5 – so this is a couple of pages in – this is the breakdown in the pie
35 chart at the bottom of the page about reportable incidents. And the largest group of

reportable incidents is “unauthorised use of restrictive practices”. And that covers a range of matters, including, if you look at the pie chart, chemical restraint; is that right?

MR HEAD: Yes, that’s correct.

5 MS EASTMAN: And environmental restraint.

MR HEAD: Yes.

MS EASTMAN: Is environmental a euphemistic term to deal with physical restraints? What does that mean?

10 MR HEAD: No. Environmental restraints – so physical restraint – in fact, each of these categories on that pie chart are categories that are referenced in the Behavioural Support Rules. They’re the generally used definitions that have existed historically. Chemical restraint refers to, typically, the use of psychotropic medications for dealing with certain behaviours. Environmental restraint is really anything that inhibits the freedom of a person to move around in their own environment, etcetera.

15 So it can include locked cupboard doors, etcetera. It’s – this is mentioned in the report, but it’s a feature of the transitional arrangements that – that providers must notify us – well, it’s a feature of the arrangements generally, but it has a particular effect during transition – we must be notified of every instance of an unauthorised use of a restrictive practice.

20 MS EASTMAN: So does this account for the very steep increase in numbers? So – and I will just round up – about 1,600 in the period 1 July 2018 to 30 June 2019, and now over 65,000 in the period 1 July 2019 to 30 December 2019? Just on first blush, that looks like an astonishing increase in reports of unauthorised use of restrictive practices.

25 MR HEAD: Yes. It - - -

MS EASTMAN: And, again, that’s just a little over on the page of the infographic.

MR HEAD: So there are three principal things that sit behind that. One is the matter I was just referring to. If a person is on a regular – if they’re prescribed, regularly, a psychotropic medication that is covered by these arrangements and

30 there’s no authorisation process in the jurisdiction that they’re based in, because States and Territories still authorise the use of restrictive practices, that’s part of the scheme, and if there is no behaviour support plan in place, every instance of that is a notifiable instrument – so is a notifiable – reportable incident. If somebody is on medication twice a day, then, at the end of the week that is 14 reportable incidents

35 for – for that person.

MS EASTMAN: Is that workable for your Commission?

MR HEAD: Well, it's a challenge, but it is – I think – so we've tried to make sure that the process of complying with that obligation is as straightforward as possible, so that it's workable for providers and us, but it is giving us a line of sight to what I think is a very, very critical issue. The behaviour support framework is designed to, over time, reduce the use of restrictive practices and, ultimately, eliminate the use of restrictive practices and notwithstanding the impacts of different arrangements, the fact that the requirement to have behaviour support plans is new, etcetera, this is giving us information on the extent of practices that are out there. And I think it's very helpful in terms of driving some of the other work we do, and will assist the Commission, both in its own right, and in our collaboration with others within government and outside of government, to do some very positive work in this area.

MS EASTMAN: Well, what – this looks a rather grim figure. What positive work can be done and what is the Commission's role in seeking to reduce the number of unauthorised use of restrictive practices?

MR HEAD: So, there are a number of elements to our role. One is general oversight of behaviour support practitioners. So if you're a – if you're a provider providing behaviour supports you must be registered. In addition to the core module of the practice standards, you will have to be audited against a module that deals specifically with restrictive practices. People who are subject to those practices will need to have a behaviour support plan in place. This is very crucial. I think it was suggested at some point in evidence I was listening to that the behaviour support plan sits alongside or complements what's happening in terms of the prescription of psychotropic medications. But, in fact, the behaviour support plan ought to be the thing that contextualises what's really driving a person's behaviour, what – what's happening for a person. It should provide the – the underpinning insights for an individual about what their behaviour means, what to observe, and, therefore, how do you make sure that in any use of a restrictive practice that's understood rather than defaulting to some kind of restraint.

So we oversee the framework, we develop – we have developed a capability framework for behaviour support practitioners; people requiring behaviour supports, as I've said, only provided by registered provider; a behaviour support plan in place, produced by somebody who's got the right capabilities to produce it; an obligation on providers to report any unauthorised use. We're also leading work with the States and Territories around a nationally consistent approach to the authorisation processes that States and Territories use. So this is a very big program of work for us. And some of the early research work that the Commission has initiated relates to the use of restrictive practices and more appropriate management strategies, but also specifically, in terms of the interests of this hearing, one of those projects relates to the use of various types of medication for behaviour support for people with autism spectrum disorder.

MS EASTMAN: All right. This may be a matter we will need to come back and explore with you - - -

MR HEAD: Yes.

MS EASTMAN: - - - on another occasion. Just in the time that's available this afternoon, I just want to deal with - - -

5 COMMISSIONER SACKVILLE: We can go – if it's convenient, we can go for a little longer.

MS EASTMAN: I want to focus the Commissioners on the reportable deaths. So I don't want to lose time to focus on that issue.

COMMISSIONER SACKVILLE: All right.

10 MS EASTMAN: But if there's particular matters that we need to come back to, we can do that.

COMMISSIONER SACKVILLE: Yes. Well, perhaps Mr Head might be able to help us on another occasion. There are a whole range of issues, I think, that, perhaps, we should be exploring.

15 MS EASTMAN: Well, I think it is fair to say that some of the work that the Royal Commission will need to do is to look at the practices of the registered providers, and so that's an area where I think there will be an opportunity to explore in further detail the use of restrictive practices. We've got lots of questions, like the use, for people with intellectual disability versus other cognitive disability. But I'm mindful of all of those matters but also mindful that we're coming to the end of a fairly long day. So

20 can I move to reportable incidents in relation to death and - - -

COMMISSIONER ATKINSON: Before you do, Ms Eastman.

MS EASTMAN: Okay. I'm going to sit down for a minute.

25 COMMISSIONER ATKINSON: I'm sorry to interrupt. But just one thing, if I could ask, Mr Head, perhaps this is something you could let us know about rather than answer today. But 15 per cent of your complaints come from support workers or service providers. You've talked about the programs you have to assist people with disabilities or encourage people with disabilities to make complaints, but I've also heard, in community forums, concern by support workers about loss of their job if they make a complaint. And so I would be interested to know – but not on this

30 occasion, but just put it on the table – what encouragement and support you give to support workers to make complaints about inappropriate practices or abuse or neglect that they see because they're often people in a very good position to see it, but also worried about their own job security.

35 MR HEAD: So the short answer is a lot, and we can provide more information on that, and there are - - -

COMMISSIONER ATKINSON: Thank you.

MR HEAD: - - - protections in the design of the framework for workers who are doing the right thing in supporting people with disability to speak up.

COMMISSIONER ATKINSON: Thank you. Yes, Ms Eastman.

5 MS EASTMAN: So in the information you provided to the Royal Commission for your report earlier this week, among the reportable incidents, which is a report of any death, there are 432 deaths reported. And this is for the six-month period up to 31 December 2019.

MR HEAD: Yes.

10 MS EASTMAN: Did that number cause you any concern or alarm?

MR HEAD: Yes. And the reason we have a reportable incidents scheme is to understand when serious things occur within the system. The “death” refers to any death in – in connection with the delivery of disability supports and services.

15 MS EASTMAN: Is that – sorry to interrupt you there. Is there any data collected by the Commission as to deaths that might be categorised as preventable deaths?

MR HEAD: So the Commission – well, part of the reason that we commissioned Professor Trollor to do the scoping review that’s referred to in my witness statement is to understand the extent of preventable deaths that had been identified in pre-

20 Commission collects, currently, a lot of information about the circumstances that lead to a death. We register an interest with the Coroner, if something is a coronial matter, around the cause of death.

MS EASTMAN: Well, just – don’t you have to notify the Coroner of all deaths - - -

MR HEAD: Well - - -

25 MS EASTMAN: - - - not just deaths of interest?

MR HEAD: So the obligation on – so the Commission oversees a provider’s management of any serious incident including a reportable death, and that includes ensuring that the provider has notified anyone they’re required to notify. If we are at all concerned about the circumstances of a matter, then we may seek further
30 information from the Police. We may formally register with the Coroner that we want to be advised when the Coroner has completed any work. Sometimes, with some matters, there will be a need for the Commission to investigate certain things using its powers and also for - - -

MS EASTMAN: And what would those matters be?

MR HEAD: So if it transpired that something had occurred that had both a criminal element and an element that related to serious compliance issues with the framework, then I would expect the Police to do their work, but also the Commission to be looking at all of those things that related to breaches of the quality and safeguards arrangements. So - - -

MS EASTMAN: How does the – how does your Commission do that?

MR HEAD: We have extensive compliance and monitoring and enforcement provisions in the Act. We have investigators who can undertake investigations. We collect information, initially, through a 24-hour report. So, with the exception of the use of unauthorised restrictive practices where there is a five-day reporting obligation, all other matters have to be reported to us within 24 hours.

MS EASTMAN: And that includes the death of anybody in the care of a provider – a registered provider; is that right?

MR HEAD: Yes, that's correct.

MS EASTMAN: But you don't pick up any reportable deaths outside registered NDIS providers?

MR HEAD: No, it's an obligation for registered providers related to NDIS participants being supported by a registered provider.

MS EASTMAN: And what about unregistered providers?

MR HEAD: Well, unregistered providers are part of the NDIS system, able to be unregistered because the people who are using them are self-managing or partially self-managing. So the process that the NDIA goes through where – when people come into the Scheme, assesses people's capacity to self-manage, and the supports that unregistered providers are providing are typically low-risk support. So people who are, you know, in supported accommodation, people – I mean, there are mandatory registration groups for certain things, but also the whole design of the regulatory framework relates to or is underpinned by risk. And unregistered providers are not in the system to provide supports that have a high level of risk attached to them.

MS EASTMAN: All right. So coming back to where a death is reported within a period of 24 hours, what internally happens as to whether that death will then be the subject of a specific investigation by your Commission?

MR HEAD: So when the initial report comes in, the Commission, in receiving the report from the provider, is concerned to ensure that there's no related safety issue for anyone else who may be receiving supports. It's concerned to make sure that the provider has notified anyone that they are required to. That might be the Police, it

might be the child protection agency. Of course, that family supporter's carer's are appropriately advised. We collect information on the circumstances leading up to the death. We collect information on those things that are important to know about whether or not there was any pre-existing issue, information on health assessments, on the medications that somebody was on. There's a rather lengthy form. But the priority in the first report is to make sure that the provider is doing everything that's required of them to manage the situation and its implications. And providers are required to provide an additional report at five days. It may be in respect of some reports that the nature of what's reported might cause the Commission to start examining something even while those other processes are going on. If something appeared to us to suggest that there was some form of gross negligence or misbehaviour of some sort.

MS EASTMAN: Well, why wouldn't something of that nature be referred to the Police - - -

MR HEAD: Well, it would be.

MS EASTMAN: - - - rather than be dealt with by the Commission itself?

MR HEAD: No. The point I'm making is anything that needs to go to the Police is notified to the Police. And there may also be things – so you may have a provider that provides supports in multiple places. And where, for instance, there might be a pattern of complaints or reportable incidents. One of the things that's quite unique in this scheme is we have not only data coming in from reportable incidents, but from complaints from audits. And we also have the power to take action, not just report on these things. So we may, in addition to any of those other things that must happen like notifying the Police, also decide that there are things that the Commission wants to examine around compliance issues more generally.

MS EASTMAN: And we've heard some evidence that family members sometimes are not contacted by the NDIS or your Commission after the death of a loved one. Is there a particular practice in terms of when the Commission is in contact with family members?

MR HEAD: So, typically, we, in receiving a report, would ensure the provider had spoken to the family. We don't – at the point that we decide to investigate something in addition to anything that is occurring through a coronial inquiry or the Police, we would, as a matter of course, speak to the family. And I am aware of the evidence related to this. And I have also previously had contact from the mother of a participant who was – would have preferred the Commission to have reached out to her.

It's not the case, I think, that everyone would welcome an approach from the quality and safeguarding regulator around the death of a loved one if there was no cause for concern on the part of that person for the supports. But I do think that the

observations that have been made about this suggest to me that we need to be much clearer in our communication to participants' families about the sorts of things where the Commission would initiate contact.

The capacity for anyone to ring us about any concern at any time, whether we've

5 contacted them or not – and, indeed, that could include a person indicating preferences about how they would want to be contacted in certain circumstances. And I'm also aware that the National Disability Insurance Agency does – has an approach to communicating in these circumstances. And I think it will be important for me to work with them to make sure that we have quite a coordinated approach.

10 MS EASTMAN: Now, it appears from the evidence that the Commission is becoming a place where very important data is collected about deaths and cause of death in Australia. And you've picked up some of the reporting obligations previously dealt with by States and Territories; is that right?

MR HEAD: So not all – well, the majority of States and Territories did not have

15 comprehensive review functions. Some States and Territories had comprehensive reportable incident schemes. We, of course – I think it's generally accepted that we will be collecting, typically, more information on more serious matters that includes deaths, and we will be doing it in a uniform way across all jurisdictions. So this is quite a stepped change.

20 MS EASTMAN: And once you have that data, how will the Commission use that data to analyse preventable deaths and to analyse and develop policies or practices that might lead to preventable deaths into the future? And I'm just mindful of the time, but those are my final two questions.

MR HEAD: I think the thing I would want to say at the beginning of my response to

25 that is that the Commission is action-oriented around these very important issues. So the reason I commissioned Professor Trollor to do his work is because when I took up the office it was apparent to me that there had been some review work undertaken before. And some of that work had been undertaken in some jurisdictions over a long period of time. And it appeared to be saying the same sorts of things about the

30 causing of preventable deaths. So the driver for commissioning Professor Trollor to do that work was a desire on the Commission's part to be able to use its regulatory toolkit to drive an agenda of action where that action was directly related to the known causes of preventable deaths. And the witness statement – I think my statement goes into some detail about some

35 of the things that we will be doing in that area and, in fact, have already started to do. It is, I think, apparent from Professor Trollor's work that many of the things that require interventions have been well established as problems for a long time. The Commission's role is to regulate providers. And we believe that there are significant opportunities to drive different practices around some of these risks in providers, and

40 that the collection of data that we will do in respect of these functions will allow us

to do a couple of things over time. One is understand the effectiveness of the interventions, whether or not the things we are doing, creating the reductions in preventable deaths that they should, but also allow us to observe any new issues. The other point I would want to make about that is that, because we're receiving
5 reports of other serious incidents, I think the information that that gives us about problematic organisational behaviour, a range of different things that might signal to you that there's a problem in the way a provider is approaching things generally, can also assist in the prevention of preventable deaths. So some actions are quite specific around things like meal time supports, all of those things. But I think understanding
10 more broadly whether a provider typically trains their workforce well, whether or not they actively encourage people to make complaints, whether they're responsive when the Commission raises issues through compliance activities, all help us to create different kinds of environments that are – where these preventable causes are significantly reduced.

15 MS EASTMAN: That answer prompts me to ask you another question. And that is, will there be transparency? So will the community be able to see the way in which you've collected the data, but, more importantly, the analysis of that data, but also any action taken? Will that be all publicly available?

20 MR HEAD: Obviously, we have to be sensitive around things like de-identification of certain data. But I think the fact that the Commission, even if its earliest months and operating in two jurisdictions, was already publishing data on things like reportable incidents proactively, indicates that we are strongly committed to being transparent. The work that Professor Trollor did for us, I've indicated in my witness statement, has been distributed very widely, not just within the direct part of the
25 system that the Commission has responsibility for, but widely across government and expert organisations, academia, community organisations, because we want the information out there. We want – this is the reason we're doing this is to change things.

30 MS EASTMAN: All right. Commissioners, I think, just given the time, I'll finish with my questions. Are there any questions from the Commissioners?

COMMISSIONER BENNETT: I have one.

MS EASTMAN: Commissioner Bennett.

35 COMMISSIONER BENNETT: I just wanted to be really clear, Mr Head. We heard from some witnesses over the two weeks that talked about their children dying as a result of lack of or inappropriate treatment that they felt had occurred through the health system. If that child was – died through something that happened through the health system and was also receiving an NDIS package, would that be reported as a death with you?

MR HEAD: So the way the regulatory arrangements work is that the obligation is on the provider to notify us of a death that occurs in connection with the provision of disability support. So where there's some kind of causal relationship between the way the supports were provided. So there's – so it limits, to those things that are
5 related to disability support provision, my powers to investigate.

So something that occurred in the hospital system is outside, although where I was, I understand from having posed the question myself, that if I'm wanting to satisfy myself of what the cause of something was where it's not clear, I might have some capacity to use some of my information-gathering powers to answer the question
10 about whether something was connected to supports where there was also something that had happened in a hospital. But I don't have the powers to investigate things that happen in deaths that occur in hospitals.

COMMISSIONER BENNETT: So does that mean that you could draw the conclusion that most of the deaths that are reported to you are of people with disability living in group homes or residential where there is a more total paid
15 provider arrangement around their lives?

MR HEAD: So it's certainly the case that the deaths that we're – that are reported to us here are much more likely – and this is evident in Professor Trollor's work – to be people living in supported accommodation with fairly high intensity needs. I
20 don't want to be more precise than that in terms of breaking down the information, but the deaths that are reported to us are those occurring in the disability system. And you are right in indicating that many of those would relate to living in supported accommodation.

COMMISSIONER BENNETT: So - - -
25 COMMISSIONER SACKVILLE: The initial – sorry – the determination as to whether there's a causal relationship between the death and the provision of relevant services is left to the service provider, I take it?

MR HEAD: Well, the service provider is required to report to us. We - - -

COMMISSIONER SACKVILLE: If there is a causal connection?
30

MR HEAD: That it – that is correct. That's the way the obligation is framed. Although this question, I should say, comes up in most of the – I do a lot of the provider briefings personally, particularly during this transition process, and we have strongly encouraged people, where they are uncertain in respect of any category of
35 reportable incident, to err on the side of reporting. Counsel Assisting asked me, I think, early on, about the number of things that are driving the increase in reportable incidents. One relates to the issues related to restrictive practices that I spoke about, but it's also evident to us that the fact that we are speaking to people about their compliance obligations is causing people to look at whether or not they are reporting

everything they're required to. And part of the Commission's development of its data and analytics capacity is a – the fact that we will be able to draw statistical inferences of what we would expect to see in different parts of the system, and where – and where there appears to be under reporting. I've got a very good array of

5 regulatory tools that I can use to require a change in behaviour. So – but you are correct, that the obligation is to report a certain type of thing, but, typically, providers, I think, increasingly, are erring on the side of caution, and we're encouraging them to do that.

MS EASTMAN: I think Commissioner Galbally had a question.

10 COMMISSIONER GALBALLY: I just wanted to raise the issue of community visitors, because it has come up on numbers of occasions. And my understanding is that States are responsible for providing them and some have continued and others haven't with the – and so I just wondered if you had any plans to have a national scheme?

15 MR HEAD: So - - -

MS MORGAN: Excuse me, Commissioner I apologise for interrupting.

COMMISSIONER GALBALLY: Sorry. Do you just want to use the

MS MORGAN: Of course. Thank you. This is one of the topics that Mr Head will address in writing that came up specifically yesterday.

20 COMMISSIONER GALBALLY: Yes, I'm aware of that. I'm just – he was going to address the specific concerns, as I understood it, whereas I'm sort of asking about his future plans - - -

MS MORGAN: We can also - - -

COMMISSIONER GALBALLY: - - - through the national scheme.

25 MS MORGAN: We can take that on as well.

COMMISSIONER GALBALLY: Okay.

MS MORGAN: We're just conscious of the time, Commissioner. It will all be dealt with in – as one topic, if that's appropriate. Otherwise, I'm sure Mr Head is happy to answer your question.

30 COMMISSIONER SACKVILLE: That is left in a state of ambiguity, but you interpret it how you wish.

MR HEAD: Well, I might just say briefly that our focus at the moment is working with community visitor schemes. And we accept that community visitors play a

really important role. They're constituted very differently in different States and Territories. Part of switching on the Commission has been developing information-sharing principles with all of the people who have a common interest in the work that we do. And we're currently finalising detailed arrangements with around 110 or 120 organisations. Those arrangements include how we will share information with community visitor schemes.

5
The Quality and Safeguarding Framework itself is new. I imagine that, once we've completed the transition and we look at what bits are working well and what bits need adjustment, that how things like community visitors are working with the new quality and safeguarding arrangements can be appropriately looked at then. They are quite distinct, the arrangements in different States and Territories, and our focus at the moment is on how to make those relationships work across the existing model that the Commission has and with the existing model in States and Territories, but – but people are very vocal about the things that they would like to see developed, and I suspect that this will be a live question for – for some time.

15
COMMISSIONER SACKVILLE: Thank you, Mr Head. Does that conclude your - - -

MS EASTMAN: It does. Thank you very much, Mr Head, for your evidence. All I need to do is formally tender the statement, which is exhibit 4.32. And Ms Morgan wants to raise one issue.

20
COMMISSIONER SACKVILLE: Yes.

**EXHIBIT #4.32 STATEMENT OF GRAEME HEAD AO DATED 11/02/2020
(STAT.0048.0001.0001)**

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MS MORGAN: Commissioners, you heard Ms Rishniw give evidence about the National Disability Data Asset. She gave evidence about that this – this afternoon. The Royal Commission was told that the Commonwealth, in partnership with the State and Territory governments, is presently working to establish a National Disability Data Asset. The objective of that Asset is to improve outcomes for people with disability, their families and carers, by enabling governments and other relevant parties to share data and to better understand the needs, service, activities and outcomes of people with disability in Australia, including people with intellectual disability or cognitive disability. To assist the Royal Commission, the Commonwealth will provide a background paper on the National Disability Data Asset to assist the Royal Commission to better understand the scope, objects and implementation of the initiative.

30
COMMISSIONER SACKVILLE: Thank you very much, Ms Morgan.

35
MS MORGAN: Thank you.

COMMISSIONER SACKVILLE: And you do not have any questions for Mr Head?

MS MORGAN: I do not. Thank you.

COMMISSIONER SACKVILLE: Very good. Thank you.

5 MS EASTMAN: Thank you, Commissioners, for bearing with us for sitting a little bit later. And I am indebted to the assistance of those transcribing the proceedings and those assisting us with the Auslan interpretation.

10 COMMISSIONER SACKVILLE: Yes. And, Mr Head, thank you very much for your statement and also for the assistance you've provided to the Royal Commission generally, and I'm sure there will be more assistance to be provided. I'm sorry that your evidence was a little compressed today but I'm sure we will have a chance to follow that through - - -

MR HEAD: Thank you.

15 COMMISSIONER SACKVILLE: - - - further. Thank you very much.

<THE WITNESS WITHDREW [4.47 pm]

COMMISSIONER SACKVILLE: Shall we adjourn till 10 o'clock tomorrow?

MS EASTMAN: Yes. Thank you, Commissioner.

20 COMMISSIONER SACKVILLE: Yes. The Commission will adjourn.

MATTER ADJOURNED at 4.47 pm UNTIL FRIDAY, 28 FEBRUARY 2020

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